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ABSTRACT

The two documents contain the final report and executive summary of a 2 year study on the impact of P.L. 94-142 (the Education for All Handicapped Children Act) on nine Michigan handicapped children (5 to 10 years old) who had participated in an integrated preschool. Section I of the final report presents introductory information with an overview section and sections on P.L. 94-142, study rationale, the sample and the setting, the conceptual framework (ethnographic), and organization of the report. The second section is the bulk of the report and contains detailed information on six cases. Each case is described in terms of introductory information (brief case sketch, chronology of contacts with institutions and service programs); the case as it relates to the five provisions of the law (protection in evaluation procedures, procedural safeguards, individualized education program, least restrictive environment, parent involvement); and major issues in the case. Finally, findings on the cases are analyzed in terms of the provisions of the law. The executive summary outlines selected findings in terms of institutional responses to the Act, implementation of the central provisions of the Act, the least restrictive appropriate environment mandate, and parent involvement. Cited among study findings are the following: the county in which Ss live has not yet developed an adequate continuum of service at the preschool level for handicapped children; there continued to be very little coordination between service systems serving handicapped children; school districts were generally passive in informing parents of their own and their children's rights under the Act, despite plentiful special education services; the county offered no mainstreamed public preschool options; and when there was deeper parent involvement, there was more tension between parents and professionals. (SB)

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FINAL REPORT: YEAR 2 OF OPERATIONS (OCTOBER 1, 1979 TO SEPTEMBER 30, 1980) STUDY OF THE IMPACT OF P.L. 94-142 ON THE HANDICAPPED CHILD AND FAMILY: INSTITUTIONAL RESPONSES AND THEIR CONSEQUENCES

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1. Introduction

Overview

This report presents the findings after two years of what is designed to be a long-term study examining the impact of P.L. 94-142, The Education for All Handicapped Children Act, on handicapped children and their families. Since much of this impact is mediated by the way institutions serving handicapped children have responded to the mandates of P.L. 94-142, the study is subtitled "Institutional Responses and Their Consequences."

Our sample consists of nine handicapped children and their families, whom we have followed in-depth as they have negotiated the world of schools, hospitals, clinics, and other institutions serving handicapped children in various ways. We have interviewed parents, teachers, therapists, physicians, school administrators, the children's evaluation teams, and others. We have observed the children in their school settings. We have analyzed records, evaluations, reports, IEPs as written, and other relevant documents. And we have attended meetings where decision-making about educational placement and program planning take place. Through this multifaceted data collection we have tried to understand responses to the major provisions of P.L. 94-142 through the eyes of those affected in various ways.

The Education for All Handicapped Children Act

The Education for All Handicapped Children Act of 1975, P.L. 94-142, "represents the most important legislation for the handicapped ever passed" (Edwin Martin). Its principles, in their interpretation and implementation, are beginning to have a significant impact on the nature of education for handicapped children and youth. These principles are: zero reject, the right to be included in public education programs; non-discriminatory classification, the right to be fairly evaluated; individualized and appropriate education; least restrictive placement, the right to normalization; procedural due process, the right to protest; and participatory democracy, the right for parents and others to participate in decision-making processes (Turnbull & Turnbull, 1978).

The central provisions of P.L. 94-142 relate closely to the above principles, and are commonly seen as the following: (1) protection in evaluation procedures; (2) procedural due process; (3) individualized educational program; (4) least restrictive appropriate placement; and (5) parent involvement. These provisions shape a mandatory process of multi-faceted evaluation, planning for placement, placement decision-making, designing of an individualized program to meet a child's needs, implementation of that program, periodic review of a child's progress, and periodic review of that child's program, including re-evaluation.

The passage of P.L. 94-142 represented the culmination of a struggle that parents of handicapped children, advocacy groups, professionals, and others waged for over two decades, principally in the courts, but also through the legislative process and in the federal bureaucracy. Precedent for the law emerged out of the civil rights litigation of the 1950s and 1960s, and out of a series of court suits in which it was found that the constitutional rights of large number of handicapped children were being denied by local and state school systems (Gliedman & Roth, 1978).

Rationale for the Present Study

One of the provisions of P.L. 94-142 was for the Bureau of Education for the Handicapped (now the Office of Special Education) to administer the Act and evaluate progress in implementation, reporting findings periodically to Congress. A set of questions was developed, relating "to the evaluation requirements of the Act and to the Congressional findings which led to the Act" (BEH, 1979). Among these were questions on the consequences of implementation of P.L. 94-142--administrative, fiscal, and attitudinal reactions; and a question on the extent to which the intent of the Act was being met, related to the principles outlined above. The present study was funded by BEH to provide information that would contribute to answering both those questions. Specifically, the study was funded to examine the impact of P.L. 94-142 on the lives of the intended beneficiaries--handicapped children and their families.

In-depth study of a small number of handicapped children and their families over a long period of time has proven to be an excellent vehicle for truly entering the world of these children and their families to gain a sense of the human impact of a particular law and its accompanying regulations. And in entering their world, we have also entered that of their teachers, administrators, therapists, advocates and others involved in shaping and providing educational and related services. It has not been difficult to gather data: the handicapped children themselves, their parents, teachers, therapists, administrators and all others involved in the educational process all care deeply about the effectiveness and appropriateness of that process, and have been glad to share their experiences. By and large, differences in perspective tend to be honest differences, with the best interests of the children in mind.

Yet it has also been crucial to acknowledge and come to terms with the fact that P.L. 94-142 is not being implemented in a vacuum. The fifty states and their 16,000 school districts have had their own approaches to meeting, or failing to meet, the needs of handicapped children and youth for a long time. Also, as has been widely noted, appropriations for implementing the mandates of P.L. 94-142 have been well below authorization levels. Thus, many states and districts have been given increased responsibility to serve handicapped children, without a proportionate increase in resources to do so.

The Sample and the Setting

The nine children in our study come from a larger group that all participated in an integrated preschool program run by a non-profit educational institution in the mid-seventies. As will be seen in the case studies themselves, this common experience had some influence on the subsequent educational history of all these children. But the nature of that influence varied widely. The children in the sample live in widely disparate communities in southeast Michigan, come from a variety of family backgrounds, and represent a wide range of handicapping conditions.

In addition to all having participated in the preschool program, all the children in the study have been influenced by the fact that since 1973 Michigan has had its own special education law, P.A. 198. This law was designed to be implemented immediately, and by 1975-76 most local education agencies (LEAs) in Michigan were making serious attempts at compliance. P.L. 94-142 and P.A. 198 are quite parallel in their intent and most of their provisions. However, the Michigan state law differs from the federal law in two notable respects: first, the state law mandates educational services for handicapped children from birth to age 25, while the federal law mandates services from ages 3 to 21 (to be implemented by fall 1980, state law permitting); second, the development of an Individualized Educational Program (IEP) in Michigan is divided into a two-stage process, requiring two separate committees: an Educational Planning and Placement Committee (EPPC) and an IEP committee. The regulations interpreting P.L. 94-142 require the placement decision to be based on the IEP; thus it cannot be made until the IEP has been finalized. In this area, at that time, Michigan appeared to be out of compliance. The state has since combined the two-stage process into one, with placement decisions being based on the individualized educational program.

This latter difference between the state and federal laws deserves some careful explanation, both to enhance understanding of events described in the cases, and because there has been some question as to whether in fact Michigan is acting in compliance with the intent and the letter of P.L. 94-142 in this area. In Michigan, the Educational Planning and Placement Committee is the body responsible for making decisions about eligibility for special education services, and about appropriate placement and services to be received. The decision about placement--for example, in a self-contained special education classroom, a mainstreamed classroom, or a shared-time program--precedes the formulation of educational goals and objectives for the year. These latter are formulated by a second body, the IEP committee, at a later date. The IEP committee is usually a subset of the EPPC, and formulation of the IEP is seen as part of the process of implementing the EPPC decisions. Often, in practice, the IEP is prepared by the educational specialists most closely involved with the child's program, and reviewed by the parents. Rules applying to the composition of the EPPC in Michigan are the same as those for the group preparing the IEPs in the federal statutes.

The cases presented and analyzed in this report thus reflect the impact of Michigan's special education law at full implementation, and P.L. 94-142 at an early stage of implementation. Because the Michigan Law, P.A. 198, and P.L. 94-142 are similar in intent and procedures outlined, there is no sharp demarcation in procedures in use prior to 1978 (the implementation date mandated for P.L. 94-142) and since then. In fact, the cases could be said to illustrate the impact of P.L. 94-142 at relatively full implementation, since the state law was implemented in 1975.

A Note on Our Conceptual Framework

While broadly speaking our research methodology can be considered ethnographic in approach, our data collection and analysis has actually been guided by very directive information needs. The case studies do not represent, by any means, the full story of nine handicapped children and their families. Rather, they focus on a specific aspect of that story, the effects of one federal law and its regulations on the lives of these children and the nature of services received. Nonetheless, we have attempted to examine those effects, to the extent feasible, through the eyes of those involved in various ways in the children's lives. We have tried to understand and internalize their perspectives, rather than interpreting what we have seen in the light of our own experiences and expectations.

It has proven particularly difficult to not become advocates for the children and their families. As we have come to know them, and they us, the demands of the study have inevitably become intertwined with the educational history of the children and their families. Two examples illustrate how this has occurred. When parents of the children in the study have asked us questions about their rights under the law, especially when they sensed that their rights were being denied, it has proven impossible not to provide them with the information they needed (for human as well as ethical reasons). In a different vein, our mere presence at EPPC and IEP meetings has been enough to alter the nature of professionals' interaction with study parents in a quite positive way, according to local advocates accustomed to participating in such meetings.

To get at the human impact of P.L. 94-142, then, we have had to become humanly involved with our study families. We have tried at all times to remember our purpose, and especially to try to understand the stresses that professionals are under, and the institutional framework in which they are responding to the law. Nonetheless, the perspectives presented in the study do tend to come more from the children and their families, and the reader should keep this in mind in evaluating the findings presented.

The Remainder of the Report

The remainder of the report will be divided into two main sections. The first will be a presentation of six of our total of nine case studies. The second will be an analysis of the findings presented in these cases, in

the context of what we see as two particularly complex and crucial provisions of the law: placement in the least restrictive appropriate environment, and parent involvement in evaluation, program planning, and decision-making. The cases selected for inclusion in this report reflect particularly clearly the issues inherent in these two provisions of P.L. 94-142. The decision to focus our analysis on these two provisions of the law was made so that our task would be manageable, and we might therefore provide timely and useful information for those struggling to make these provisions work. The discussion in the analysis does not synthesize, but rather is designed to complement, the discussion of each of those two provisions contained in the case studies.

2. The Case Studies

HELEN FARRELL

I. Introduction

Brief Case Sketch

Helen Farrell was born in May 1974. She is the younger child of John and Martha Farrell. Martha had a number of medical problems while she was pregnant with Helen, particularly during the last trimester, and Helen was born approximately six weeks premature. An emergency cesarean section was performed, as Helen was in the breech position. Martha's medical problems, and respiratory complications in Helen after birth, led to periodic monitoring of Helen by the high risk clinic at a local university hospital during her first year. Before she was a year old she was diagnosed as having cerebral palsy, affecting primarily her lower extremities. Contact with service agencies began immediately.

Beginning in February 1975, Helen has had regular physical and occupational therapy services; participated in three different early intervention programs, at times concurrently; and this year, 1979-80, participated in two primary programs, one mainstreamed, the second for physically or otherwise health impaired (POHI) children. She has had regular evaluations in all areas--fine and gross motor development, perceptual development, and cognitive development. And she and her parents have had easy access to a range of specialists in all areas pertinent to meeting Helen's needs.

Yet while Helen has benefited enormously from the wide range of services available in the area in which she lives, a number of problems with a central institution serving Helen--the POHI school where she has received all her physical therapy (P.T.), occupational therapy (O.T.), and some classroom services--have caused the Farrell's much pain, anger, and confusion. Their problems appear to have been largely resolved at this point, due in large measure to some of the rights recognized for parents under P.L. 94-142. Yet the pain these problems caused Helen, her parents, and at least some teachers and therapists, has left a residue of bitterness that will be hard to dissolve.

As will be illustrated in detail, Helen's case reflects a number of themes related to the interpretation of P.L. 94-142. The Farrells are knowledgeable, active, highly involved parents, whose determination has done much to assure that Helen has had the best medical, therapeutic, and educational services available. Yet this same determination, activism and knowledge (Martha is a nurse) has led to conflict with the previously mentioned institution about who is to decide what kind of program is best for Helen. While aware of and using their rights under P.L. 94-142, the Farrells have been made to feel the full "moral and practical power" of professionals to make fundamental decisions concerning their clients' lives. While most of the professionals involved with the Farrells have been extremely

sensitive, caring, and responsive, at least a few have felt that it was their right and responsibility to determine Helen's needs (see Gliedman & Roth, 1980, Chpt. 8). These latter professionals have used the evaluation and placement process outlined in the law to impose their authority over the Farrells.

A second theme reflected in Helen Farrells' case has been the difficulty of determining least restrictive appropriate placement. Different placement choices have always been available to Helen, and all have meant trade-offs among various areas (cognitive stimulation, socialization, quality of physical and occupational therapy). Working these choices out has meant the fractionalizing of Helen's full program. A third theme reflected in Helen's case has been the relationship between public and private schools providing services to her. Helen has attended a private preschool, and this year kindergarten, half-time since she was two-and-a-half years old; the public POHI school since she was four-and-a-half. Questions of responsibility, cost, communication, and coordination of services have had to be dealt with constantly.

The Farrells as a family are very tight-knit, and fully involved with each other. Economically they are not at all well-off for the time being. But they have created and maintain a warm, stimulating, child-centered household, and the security of this home-base is reflected in the children. John Farrell is completing his college education, and currently works as a counselor. Martha Farrell is a nurse, and while she could easily have been fully employed during the children's early years, she has preferred to work on-call, or part-time. She has been more directly involved in school affairs than John, although they talk through important decisions thoroughly together. Johnny is eleven months older than Helen, and has contributed to his sister's development in many ways. He has served as a model and guide for her in the preschool they both attended, and now in the elementary school. And they are clearly friends to each other as well as siblings.

Helen's main attributes, for the observor, are determination and intelligence. She is at times extremely independent, refusing help; at times she seems to welcome assistance, especially from adults. Socially, she has always been extremely popular among her handicapped and non-handicapped peers. A tendency by peers and adults to help her and dote on her--she is physically extremely small and pretty--has created, if anything, impediments to her quest for autonomy.

A Chronology of Contacts with Institutions and Service Programs

Martha became pregnant with Helen three months after Johnny's birth. That first pregnancy had been a difficult one, and Johnny was delivered through cesarean section, as he was in the breech position. After Johnny's birth, Martha had a borderline high blood pressure condition, and there was concern over possible toxemia. When it was discovered she was pregnant again, she was referred to the High Risk Clinic at the local university

hospital. The clinic monitored her pregnancy carefully, placing her on a low-sodium diet, and checking amniotic fluids in the second and third trimester.

At the first check, it was determined that the fetus' lung capacity was possibly underdeveloped, but at the second check that problem did not appear. Ultra-sound scanning was done, to determine the position and size of the fetus, and the potential due date. Almost six weeks before Helen was due to be born, Martha began to retain fluids, gaining 7-8 pounds in only a few days. She also had severe headaches. She was immediately admitted to the university hospital, put on intravenous fluids and given diuretics. A day after being admitted, she had an emergency cesarean section, and Helen was born, in the breech position like Johnny, and six weeks premature.

Helen was small at birth, weighing five pounds seven ounces. Due to respiratory problems and her birth history, she remained under observation in the Neo-Natal Special Care unit of the hospital for ten days, also receiving respiratory therapy. After Helen came home, the hospital's neo-natal clinic continued monthly monitoring of Helen, primarily concerned with a mild anemic condition, but also concerned about Helen's muscle tone. Looking back, Martha remembers feeling concerned also about something she couldn't quite put her finger on. Helen had an inordinate startle reflex, and seemed very tense. It was, for instance, very hard to bathe her because of her tenseness. Helen also had what Martha felt was high muscle tone.

At the eight month follow-up examination, Helen's pediatrician mentioned explicity for the first time his concerns about Helen's muscle tone. He did not mention cerebral palsy during that examination. Upon returning home, Martha reports thinking about what the pediatrician had said, trying to put things together. As she was describing the pediatrician's concerns to John it suddenly dawned on her: "Helen has cerebral palsy." She immediately called the pediatrician and asked him, "Are you telling me she has cerebral palsy?" She recalls him replying, "...well, cerebal palsy is a wide, catch-all term, it can mean anything from the slightest tenseness to complete disability... I guess you can call it cerebral palsy in Helen's case." Sensing their concern, he referred them to another doctor working in Pediatric Rehabilitation at the hospital. This doctor confirmed a diagnosis of diplegic cerebral palsy when Helen was nine months old. Martha remembers the conversation with this physician vividly:

> "...The doctor was very reassuring and I remember--it's funny, because you have these little fantasies in the back of your head about when you have a child, what they're going to be like. I had a friend whose little girl took ballet; and that was always kind of in the back of my head, that someday I'd have this little girl and she'd be wearing this little dress and she'd be doing the ballet. One of the first things the doctor said, which was really devastating at the time but probably was the best thing anyone could have said to me, he

said: 'I can't look into the future, but I've seen a lot of kids with CP and Helen is not severely affected. She's not going to be a model or a ballet dancer, but people won't turn and gawk at her when she walks down the street either. She's not going to be real graceful, but hopefully she will walk and she will do things--it'll just take her longer.' And the fact that he mentioned the ballerina was very good, because it just brought us down to where we were and what we had to expect."

Helen was re-evaluated by Pediatric Rehabilitation staff in January 1975. Improvement in her gross motor ability was noted, and the specialist who had confirmed Helen's cerebral palsy (C.P.) felt "quite encouraged" as to her ultimate prognosis. He recommended to the Farrells that they participate, at least temporarily, in an infant stimulation program run by an Institute for Research and Intervention in Mental Retardation related to the university. Martha was hesitant to get involved in this program, because of the implicit labelling Helen would get from involvement; but it was the only infant program of that type at the time.

The program at this Institute was multi-faceted. For one activity, mothers and fathers brought their children to weekly group sessions in which physical and occupational therapists demonstrated activities they could engage in with their children; for example, ways to help relax or stimulate the infant, comfortable positions, and related things. Weekly home visits by Institute staff also included helpful advice on concrete and more subtle issues, and alot of support. The program was designed to make the parents feel competent. Martha notes, looking back, "When you have a child with a disability and you can do something about it, even if it's just doing exercise once a day, I think you feel so much better about it."

The program also had a parents' group, which met monthly to discuss particular issues. It was at one of these meetings that Martha first learned about P.L. 94-142, her rights as a parent, and Helen's rights to a free appropriate education. It was also at one of these meetings that she went through a mock Educational Planning and Placement Committee (EPPC) meeting. Finally, Helen was periodically evaluated in different areas by Institute staff. The Farrells remained in this program until mid-1976, utilizing all of its services except physical therapy. They speak highly of the program to this date, and still use the Institute staff as occasional resources, counselors and evaluators.

During one of their first contacts with the Pediatric Rehabilitation Clinic at the hospital after Helen was diagnosed as having C.P., a nurse recommended to the Farrells that they contact Jean Rauth, a physical therapist who specialized in infant therapy and was working with another local college that had a special education school with an active POHI program. Jean Rauth observed Helen, at age 9 months, and disagreed strongly with the optimistic prognosis for Helen offered by the pediatrician at the Pediatric Rehabilitation Clinic. She felt Helen was moderately severely

to severely affected by her C.P., and would need alot of therapy. She noted in her report that " I am rather surprised that Helen performs as well as she does, since she has moderately severe spasticity."

Helen began receiving about two hours a week of physical therapy from Jean Pauth in March 1975. The Farrells continued participating with Helen in the university Institute program. A report in June 1975 indicated that Helen was making good progress, and the Farrells were happy with the services Helen was receiving. This same combination of services continued for Helen during the 1975-76 school year. No public education agency was involved in planning, placement or programming for Helen at that time, and no one involved with the Farrells suggested contacting the public schools for any reason. An April 1976 evaluation by the Institute staff indicated that Helen continued to have significant gross motor difficulties, due to her spasticity and related problems, but that she was making progress; that she was showing excellent cognitive and language development (above average for her age); that there was some lag in perceptual abilities, and that her smallness in physical size continued to be a concern.

In June 1976 the university Institute's funding for its infant stimulation program ran out, and participating families were advised that the program was being terminated. Around the same time, in mid-May, Helen's first EPPC meeting was scheduled by the staff at the local college's special education school, in consultation with the public school's special education department. Helen was two years old at the time. A consensus was reached at that meeting that Helen would enter "phase I" of that school's early intervention program in the fall, and continue receiving physical therapy from Jean Rauth (phase I was a completely individualized program, involving parents; a child moved through four phases of the program until she was in the classroom with a large group).

The 1976-77 school year began with Helen receiving regular physical therapy, and Martha participating in a mother's group at the school. She found this group, like the other, very supportive for her. Jean Rauth was working intensively with Helen; their rapport was excellent; and Helen was making progress. Meanwhile, the Farrells were looking for a preschool placement for Johnny, who was three. A private preschool program run by a local educational research foundation was recommended to them and they enrolled Johnny there. As they came to know that program, they began to think this preschool, which ran four mornings a week, might be a good situation for Helen also. That fall the preschool had received a federal grant to initiate a mainstreamed program, and the teachers, after observing Helen, felt that she was ready. She entered that program in December 1976. (She was then two-and-a-half years old.)

During the fall of 1976, the college's special education school where Helen was receiving physical therapy began undergoing a basic administrative re-organization. Eventually, this re-organization was to have a major impact on Helen and the Farrells. For a number of reasons, some related to requirements under P.L. 94-142, the governance of the school was transferred to the local school district. Also, the school was designated as the Physically

or Otherwise Health Impaired (POHI) facility for the county, comprising ten districts. The full transition was to take more than a year. However, the Farrells began to feel some immediate consequences.

Soon after the administrative re-organization began, the school's administrators, and the staff of the early intervention program, began pressing the Farrells to use their services more fully for Helen. Arguing that they weren't a clinic, they began to press the Farrells to enroll Helen in the classroom program, in spite of the fact that the Farrells had made it clear that they preferred the private mainstreamed preschool program for Helen, and were perfectly happy receiving just physical therapy at the POHI school. The reasons for the pressure were not clear. One might have been the need for numbers justifying the school's existence and future public funding by numbers of students served. A second reason might have been professional concern that Helen wasn't getting an appropriate program at the private preschool.

In fact, the staff at the POHI school told Martha that Helen needed a "complete program" at the school. Martha noticed their attitudes toward her changing, also. They began to act much more hostile, even Jean Rauth, with whom the Farrells had gotten along very well. Martha reports that there were a number of meetings to discuss the issue:

> "...we had all kinds of people come, from the university Institute, Pediatric Rehabilitation, the private preschool program. They all said that Helen doesn't need the full day program at the POHI school, she was doing very well at the mainstreamed school. The POHI staff were saying she needed their program for socialization, a complete program....finally, they reluctantly agreed to let her come in for therapy, but there was alot of feeling, and it was very obvious; there were remarks made all along, little digs, cracks...once when Johnny and I were waiting for Helen in an empty classroom, she was in PT, the teacher came in and said, 'it's interesting that you're willing to use our facilities for babysitting your son, but not willing to let us use them to serve your daughter...'"

Martha recalls that the main feeling she had that year was fear that the hostility of the POHI school's staff was going to be turned toward Helen. It was a rough year for the family, and Martha feels that this was due to the attitudes of a few professionals. Meanwhile, Helen was thriving at the private preschool. After some initial adjustments, for example, overcoming fear of the other children, she was fitting in well, growing intellectually and socially. She was very happy to be with Johnny. The teachers at the preschool reported that she was having a very successful experience.

By June of 1977, it was clear that the POHI school staff would request an EPPC meeting for Helen for the fall. Ironically, John and Martha did not want the meeting: they were afraid that the delicate compromise they felt they had reached with the POHI school staff would crumble under the weight of

professional consensus certified by a formal placement review. Further, the classroom teacher that Helen would have if she participated fully in the early intervention program was the one from the "baby-sitting" incident, described above. The Farrells decided to prepare carefully for the meeting. They requested that a number of additional people be present, including staff from the university Institute program, the private preschool, and an advocate.

The 1977-78 school year began with Helen in the private preschool program four mornings a week, and receiving physical therapy at the POHI school three days a week in the afternoon. The EPPC was postponed, re-scheduled, and postponed again. One day in September, Martha happened to run into one of the staff from the university Institute in the hall at the POHI school while she, Martha, was on her way to pick up Helen. Martha asked this person, one of those she had requested attend Helen's EPPC, what she was doing there. She said that she had come for Helen's EPPC at 1 p.m. Somehow, the POHI staff had notified everyone of the revised meeting time but the Farrells.

The meeting went as Martha had anticipated. The atmosphere was confrontational: "us against them." There was a lot of feeling, with the POHI staff telling Martha that Helen needed their program, and Martha and other professionals present arguing that she was thriving in the mainstreamed preschool program, and only needed the physical therapy services at the POHI school. The Farrells' preparations for the meeting basically paid off. Helen was to continue in the mainstreamed preschool program mornings, receive physical therapy at the POHI school three afternoons a week, and, at the absolute insistence of the POHI staff, receive occupational therapy two afternoons a week. As Martha said, they didn't want the O.T.--she was a nurse and felt she could work on the fine motor skills with Helen herself; also, it made Helen's week too demanding physically. But they were tired of fighting.

Thus, the 1977-78 school year progressed. The hostility toward the Farrells on the part of the POHI school staff continued and deepened. As Martha notes: "there were days when I couldn't muster up the nerve to walk in the building, it was that negative." Helen continued to progress in the private preschool, but her schedule was tiring her out: "she was extremely tired, she'd fall asleep on the bus, come home and sleep some more..." Also, the occupational therapist at the POHI school began to relate to the Farrells her concern that Helen was learning disabled. In her reports, "she seemed to focus on what was wrong with Helen." (Martha feels that behind their desire to find something wrong was a desire to justify her being in the POHI program.)

The 1978-79 school year began, without formal review of Helen's placement. She continued in the mainstreamed preschool in the morning, and received P.T. and O.T. in the afternoon. During the previous year, the Farrells had been persuaded to have Helen participate informally during two afternoons a week in the classroom component of the POHI school early intervention program, "to allow therapists to observe in the classroom setting, and thus facilitate

planning for therapy." This arrangement was implicitly formalized--again, the Farrells were tired of struggling--and Helen's week became even fuller. Extremely samll in size, and using enormous physical energy to master her body, the demanding daily schedule continued to be too much for Helen. Yet, the Farrells report that the preschool experience was extremely positive for her, she enjoyed it enormously. And in order to get physical therapy, crucial to her gross motor and physical development, she had to participate in O.T. and the classroom program.

During the 1978-79 year it became increasingly clear that Helen would need corrective surgery, to release some of the extremely high muscle tension. While she had made much progress physically during the last two years, she continued to have "turning-in" problems, balance and postural problems, and alot of spasticity. In April of 1979, she returned to the university hospital for corrective surgery. During that spring, Helen's occupational therapist had mentioned to the Farrells that she wanted to so some testing of Helen, because she felt there were possible learning and perceptual problems. Martha reluctantly agreed, and then wrote a note asking the therapist to postpone testing because of Helen's upcoming surgery. The day Helen returned to the POHI school after recuperating from her surgery and a bout of chicken-pox, she came home and told Martha she had been tested.

Martha called the occupational therapist and pointed out that this was the least ideal time for her to be testing Helen--she had missed school for her operation, was recuperating from that and chickenpox, and by the afternoon, when the testing would be done, Helen was extremely tired. Nonetheless, two weeks after the school term ended, the Farrells received a report of test results from the occupational therapist. The report hinted at perceptual problems in Helen, and the possible need for her to be classified as learning disabled. The Farrells were tremendously upset--there was no evidence from her preschool program that Helen had any perceptual or learning problems.

The Farrells arranged immediately for an independent, comprehensive evaluation of Helen in all perceptual areas, to be conducted by the university Institute. The Institute had staff with national reputations in the area of learning disability. Testing took place in August 1979, and the findings confirmed the Farrells' beliefs. The findings indicated that Helen's overall cognitive/perceptual functioning (she was five years, three months old at that time) was equal to that of a child in first grade; that Helen did not have perceptual deficits; that future teachers should be aware that she may be slower in execution of some tests, but that she will accomplish them, especially if she is properly seated to perform them; and that Helen should not be held back in any way because of her physical handicap. The Farrells wanted the O.T. report removed from Helen's records, but this was not possible. They have managed, though, to have the independent evaluation included in those records.

The fall of 1979 brought major changes to the shape of Helen's educational and therapy program. As in 1978-79, there was no formal review of Helen's placement. Rather a process of negotiations over the phone and during meetings at the POHI school led to Helen's placement in the primary program (for children five to nine years of age) of that school in the afternoon, with a new teacher, and new therapists. Also, Helen entered the elementary program of the private educational research foundation five mornings a week. Johnny had entered that program a year before.

While continuing the last year's pattern of an extremely full, demanding day for Helen, the new placements eased many of the pressures on the Farrells. For one thing, the new teacher, physical therapist, and occupational therapist were much more open, supportive, and sensitive to the Farrells' concerns. They didn't impose their authority on the Farrells. And they seemed to really care deeply about Helen. (Jean Rauth, Helen's physical therapist for over three years also cared deeply about Helen, and came to be a special figure in her life.) In the mainstreamed elementary program of the private school, Helen again had to make the adjustment to a new physical environment and new children. But her and her family's whole historical experience with that institution had been very positive, and she made the transition easily.

In fact, one of the ironies of the Farrells' two years of particularly harsh conflict with the POHI school administrators and early intervention staff was the constant comparison being made in the Farrells' minds between the two institutions. Martha has said that the private school was "the only thing that kept us going during that period." For example, during Helen's operation, the children in her class all made gifts and had them brought to her. The teachers visited her, and took photos; when she returned to class she used the photos to describe the whole experience. Jean Rauth was apparently the only POHI staff member to visit her, or do something to help her through that period.

During the 1979-80 school year, the Farrells' feelings about the POHI school experience for Helen began to soften, and they began to see more positive aspects of it. The change of staff made a big difference. Also the Farrells came to see that it was just as important for the development of Helen's self-concept that she spend time with other physically handicapped children--they have needs and problems similar to hers--as with non-handicapped children. Helen herself said to Martha one day this year: "Everybody can walk and I can't." The year was a good one for Helen, with progress in all areas of development. She seemed to like both programs, and came to respond better to the physical and mental demands of a very full day.

Nonetheless, the Farrells came to feel during the spring that academically they wanted her to have one first grade program during the 1980-81 school year. "Shared-time" would possibly be more convenient for

the POHI school staff, but not for Helen. The first grade placement they wanted for Helen was the mainstreamed private school program. They liked the POHI primary program--the teachers and therapists, said Martha, "actually see her as a kid, they always have something positive to say about her." But the mainstreamed program had a full-day first grade that wasn't easily divided; and it was the least restrictive, yet appropriate, environment for Helen. The challenge was going to be to get physical therapy services, without the full program, from the POHI school.

An EPPC meeting was called for the end of May 1980, the first formal placement review in almost three years. Again, the Farrells prepared thoroughly, this time requesting the presence of two advocates, both well-known and respected in local special education circles. The POHI school principal chaired the meeting. In attendence, aside from the POHI primary staff, was one of Helen's teachers from the private school, and the Director of Special Education of Helen's home school district. A high-powered group had obviously been assembled for the meeting.

The EPPC started out with the normal routine for such meetings in this particular district. Teachers and therapists gave progress reports. The summary findings of all recent evaluations were reviewed. The nature of Helen's current program was reviewed. Both classroom teachers pointed out that Helen had made good progress cognitively and socially that year. She had become less dependent on adults, more dependent on peers. She was totally functional in class, and was only constrained by the fact that she completed tasks more slowly than non-handicapped peers. Helen's physical therapist pointed out that a continuing combination of weakness, tightness, and imbalance muscularly and neurologically was slowing progress toward independent walking. She was concentrating, she said, on the individual habits that make up walking, the quality of Helen's gait. She wanted Helen to learn to monitor her own movement. Posture, and center of gravity, were other issues. The occupational therapist was somewhat ambivalent in her report. While mentioning a number of tasks that Helen had accomplished, she emphasized that she did things more slowly than normal. Both therapists said that Helen is very functional--"she's all over the place."

Next, the principal of the POHI school laid out what he saw as the four reasonable alternatives for placement for Helen the following year. These were: regular public school, first grade full-time; regular first grade, plus support services (teacher consultant, therapists); shared-time: regular first grade and the POHI special education class (self-contained); just the POHI special education program. At that point, aware of an obvious gap in the alternatives offered, the district special education director pointed out that "parents also have an alternative available to them, which is a private program, outside the public school system; but a school-based committee would not recommend that kind of placement."

A discussion of the public school alternatives ensued, with all participants, including Martha Farrell, discussing pros and cons. It began to be clear that the shared-time option was the alternative of choice of all the

POHI staff and of the district Special Education Director. The reason was that Helen would have the best of both worlds: half-day of a mainstreamed environment, half-day of the unique services that only the POHI school could provide (for example, a POHI certified classroom teacher). The discussion turned on whether Helen could have a successfully coordinated program, with effective therapy, if the therapists had to go out to a local school to work with her. If the only need for Helen to be in a more restrictive environment was for her to receive therapy, couldn't the therapy be brought to a less restrictive environment?

At that point, one of the advocates asked Martha to express her desires for the 1980-81 year. Martha then said that she'd been very happy with shared-time that year, but was beginning to be more concerned with academics. For at least first grade, she said, she wanted to have Helen at the private school full-time, with physical therapy and occupational therapy consultation from the public schools (i.e., ancillary special education services).

The Director of Special Education, who had been acting somewhat as an intermediary during the whole meeting, then explained that Martha was in effect requesting that Helen be withdrawn from the public schools, and that the referral process for special education services for Helen would have to begin again, with another EPPC convened. She pointed out that all private schools in the area can request special education services, and that they would work through the county office to determine the equitable amount of services to go to Helen: they had to assure equal delivery, given resources, of services to public and private school children.

The principal of the POHI school then said: "this is an educational procedure for me...I came here today prepared to collectively come to a recommendation for an appropriate program for Helen...I think at this juncture we're saying that's not a collective decision we're going to make today, Mrs. Farrell is making that decision." At that point the meeting broke up into small groups.

Upon re-convening, the Special Education Director, who had in effect taken over the "negotiations", offered a compromise: while shared-time usually meant 50/50, in Helen's case they could see 60/40 being appropriate with the private school program being "60", and Helen remaining a public school student. It had been clear throughout the meeting that the director genuinely wanted the best possible program for Helen, and that she thought the shared-time option would give Helen the best of both worlds. The POHI staff, on the other hand, felt that they would have alot of problems coordinating services with the private school (which was only five minutes away) if Helen jsut used their physical therapy services. Also, they felt that a non-POHI trained classroom teacher, however well-intentioned, couldn't give Helen the kind of all-around classroom program a POHI certified teacher could. The private school teacher said that they would be glad to cooperate in any way the POHI staff felt useful and appropriate.

At any rate, Martha remained adamant in her desires, saying that she just wanted to minimize disruption to Helen's program. The Director of Special Education, in a final gesture of compromise, reminded the group that six, eight, or ten weeks into the next year they could always call another EPPC to review things, that placement is a "fluid thing." "We each have to express our judgment," she pointed out, "and I certainly respect your (Martha's) opinion." She promised to try to arrange the next EPPC before the middle of June, to determine how much public school ancillary service Helen would receive, and to begin to work out logistics of service delivery.

The meeting was an open and non-antagonistic one, especially compared to past meetings and the one previous EPPC. A less restrictive alternative than the POHI school clearly was open to and appropriate for Helen. The question then became one of degree of continued participation in the POHI program. The presence of two knowledgeable, well-respected advocates, with whom the POHI staff had had previous contact at numerous EPPCs, contributed to a spirit of negotiation. The professionals at that meeting clearly were not happy about the Farrells' decision not to use POHI classroom services. But the weight of their consensus was not enough to overcome the weight of Martha Farrells' and her advocates' consensus. The amount of ancillary services Helen actually gets from the public school POHI program next year remains to be seen.

II. The Farrell Case and the Five Provisions of the Law

Protection in Evaluation Procedures

Since Helen's cerebral palsy was diagnosed when she was eight months of age, she has been evaluated regularly and comprehensively, and under non-stressful conditions, in all but one case, to be discussed. Tests and evaluations have been conducted by the university hospital Pediatric Rehabilitation Clinic, the university Institute for Research and Intervention in Mental Retardation, and the Physically or Otherwise Health Impaired school staff and consultants. Evaluators have reportedly been professional, well-trained, and sensitive to Helen's style of functioning. Reports have been summarized in easily understandable language, for the most part. And evaluations have been conducted to provide concrete, useful information to Helen's physicians, therapists, teachers, and parents.

Two issues--one major, one minor--provide exceptions to Helen's protection in evaluation procedures. The major exception was the occupational therapist's decision to go ahead and test Helen in the areas of perceptual and learning ability immediately upon her return to school after her corrective surgery and a case of chickenpox in April, 1979. The Farrells had specifically requested that the therapist wait awhile so Helen could regain some of her strength and re-acclimate herself to school and school-like tasks. Also, they did not want Helen tested in the afternoon when she was generally fatigued. It is difficult to understand why she went ahead with the testing when she did; why she chose to interpret the ambiguous results of the testing in a way that contradicted general perceptions of Helen's functioning; and, most importantly, why she did not inform the Farrells of the testing before it was done.

Taking recourse under the protection in evaluation provisions of P.L. 94-142, the Farrells have begun efforts to have that report removed from Helen's file. Also, they arranged for an independent evaluation of Helen in the perceptual/learning area; this evaluation has been placed in Helen's files and was considered and accepted at her recent EPPC.

The second issue providing exception to adequate protection in evaluation procedures in Helen's case is a minor one, but nonetheless worth mentioning. Some of the POHI staff involved with Helen--not all--have used evaluation opportunities to focus on what Helen can't do, rather than what she can do. The negative focus has often been subtle--a matter of emphasis, a tone of voice--but it has had a strong impact on the Farrells. They know Helen has to struggle to accomplish certain tasks; but they also know that she almost always accomplishes them. Most professionals--including POHI school staff--have nonetheless been more positive in focus, while not glossing over Helen's struggles to achieve mastery of her body, and "the positive" has been a great source of support to the Farrells.

The Farrells have always had access to, and in fact have a file containing, all evaluation reports for Helen. They have also had ample opportunity to discuss evaluation plans and findings with those providing services to Helen. In general, the regularity, fairness, and thoroughness of evaluation procedures have been significant assets in the process of planning and actually implementing services to meet Helen's needs, especially complemented by the Farrells' opportunity to express their perceptions.

Procedural Safeguards

Again, with one exception, the letter, if not always the spirit, of the law has been followed in Helen's case in this area. The right of Helen and her parents to consent or refuse consent for evaluations has been observed; a uniform evaluation, placement, programming, and re-evaluation procedure has generally been used; notification of EPPC and IEP meetings has, with one exception, been provided; confidentiality of records has been assured; and, the Farrells have been aware of, though not tempted to use, the right to a due process hearing, and the right to appeal and review hearing findings.

The concrete exception to adequate procedural safeguards was the instance in the fall of 1977 when the re-scheduled EPPC meeting for Helen was held apparently without the Farrells' prior knowledge. Martha recalls being told that two alternative days were being considered, but she does not remember receiving written notification of the date finally chosen. The people the Farrells wanted at that meeting had been properly advised, and Martha's incidental appearance at the POHI school assured her participation. Nonetheless, there remains some question as to the appropriateness of holding the meeting when the Farrells had not indicated knowledge of it, or that they'd be there.

A less concrete exception to adequacy of procedural safeguards for Helen and the Farrells, but possibly a more profound one, can be found in the questions of whether the POHI school staff have followed the spirit of the law with regard to decision making about placement for Helen. During the early years of Helen's contact with them they placed enormous pressure on the Farrells to use more services than the Farrells wanted for Helen. Their implicit, and at times explicit, conditions that Helen participate in their classroom program in order to have access to therapy services made life difficult for the whole family, and physically stressful for a child already under physical stress due to the nature of her handicap. While the Farrells were never explicitly by-passed in decision making with regard to Helen, their desires were submerged by the weight of professional authority used to pressure them into accepting conditions they found unacceptable. By

combining their weight with that of two advocates, and due to the intercession of the local Special Education Director, the Farrells were able to more affectively confront professional authority in the recent EPPC meeting.

In general, nonetheless, procedural safeguards have acted to protect Helen and her parents' rights. The Farrells have undoubtedly had more influence over the decision making process for Helen than they would have if they had not had or not been aware of their legal rights to influence that decision making process, and appeal decisions they found inappropriate.

Individualized Educational Program

As has been mentioned in earlier reports of study findings, major placement decisions in Michigan are handled through the mechanism of the EPPC meeting, with IEPs having perhaps more detailed, logistical functions than in other states. Michigan's two-step process stretches out the decision making process, which has both advantages and disadvantages (to be discussed in the annual report). In considering this provision of the law for our cases, we thus must consider both aspects of the process.

Helen, who was diagnosed originally at age eight months and is now six years old, has had three EPPCs and a number of IEP and IEP reviews. Her first formal contact with the public schools was through an EPPC meeting held when she was two years of age; the meeting was initiated by the POHI school, then still part of the state university system. A second EPPC was held in the fall of 1977, a year later, and the third was held in June 1980, three years after the second.

There is some question as to why an EPPC was not called during the 1977 to 1980 period, especially as a number of placement issues have constantly been present in Helen's case. Martha reports "wanting to leave well enough alone," and also simple weariness at the constant battle to keep Helen in the private, mainstreamed preschool and primary programs. She was afraid the delicate truce with the POHI school would crumble if placement was regularly--annually--made a formal issue. It may be that the POHI school staff felt the same as the Farrells: they too didn't want to upset a delicate balance. Nonetheless, a major transition in Helen's educational life took place last fall--from preschool to primary school--with no formal placement review taking place.

From analysis of the records it appears that IEP and IEP review meetings have been conducted regularly for Helen during at least the last two school years. These were the years during which she participated in the POHI school classroom program, as well as the private school program. These IEPs have been held in the fall, the Farrells have been invited and have participated, and concrete goals have been laid out during the meeting. The IEP reviews have also been appropriately conducted, with advanced notification for the Farrells, and assurance of their participation, and with a review of goals set in the fall. Goals established in the fall have been used to guide Helen's program as far as can be ascertained.

If there has been any weakness in the IEP process, it has been the lack of involvement of the private school staff serving Helen in the preschool and primary program. There has to the present been no real effort on the parts of both institutions serving Helen to coordinate planning and provision of services. This is probably due to the fact that one of those institutions is a private school. The IEP process is viewed by public school staff as a process that they have to comply with. While the private school staff have planned an individualized program for Helen every year, they have done so because they do this for all children. In particular, the lack of input from the therapists at the POHI school as to what gross and fine motor activities and behavior are most crucial for Helen to work on has probably weakened slightly the value of her private school program.

The Farrells have had no problems inviting people that they want present at EPPC meetings, and these participants have been free to contribute. At the recent EPPC, a representative from the private school was in attendance, and made a valuable contribution to the meeting. The IEP meetings have generally had more limited participation, probably because they are viewed as operationally oriented rather than decision oriented.

Least Restrictive Environment

This provision of P.L. 94-142 has proven to be especially difficult to interpret and reach agreement on in Helen's case. The nature of her therapeutic needs has been generally clear-cut, and she has received excellent therapy over the years. A great deal of conflict has been engendered, though, over the classroom program most appropriate for Helen. The Farrells have felt that the mainstreamed preschool and primary program at the private school is the least restrictive appropriate environment for Helen. The POHI school staff have uniformly felt that their early intervention and primary classroom programs--self-contained special education classrooms, unambiguously more restrictive--are more appropriate for Helen. Physicians, therapists, and teachers from the university Pediatric Rehabilitation Clinic and the Institute previously mentioned have generally agreed with the Farrells.

What has resulted from this conflict of opinion, at least until the present, has been a compromise: a shared-time program with Helen participating in the private, mainstreamed program in the morning, and the self-contained POHI program in the afternoon. The Special Education Director feels that Helen has had the best of both worlds. Helen herself was unhappy the first year of this arrangement, happier this year, but both years a very tired child at the end of the day. The Farrells are beginning to feel that this "compromise" is a compromise with Helen's academic future, especially as she enters first grade. That is why they asserted their feelings again this year, risking a relatively satisfactory arrangement, in order to achieve an excellent one.

Since all the available evidence indicates that Helen was thriving academically and socially in a less restrictive, mainstreamed environment, what grounds have the POHI staff had for arguing that a more restrictive is more appropriate? First, they have argued that Helen can have a more successful program from a therapeutic viewpoint if her teacher and therapists are part of a closely knit team who know each other, and see each other regularly. Her physical and occupational therapy can be more fully integrated into her classroom program at the POHI school. Second, a POHI certified classroom teacher herself can more effectively meet Helen's needs. Third, there are many positive aspects to Helen being around other physically handicapped children. They are people, too, after all, and suitable peer models in their own way. Also, her "self-knowledge" needs to face that part of her life to develop realistically.

The Farrells have argued, as have others involved, that with some effort on the part of the POHI staff, effective physical therapy and classroom support can be provided to Helen in a mainstreamed context; there is no excuse for her to not be in that context. This is especially true since there are no doubts about her ability to thrive in that context. Certainly, extra work will be required of all those involved in providing educational and therapeutic services to Helen. But the private school and POHI school are only a half mile apart.

Helen's case would seem to be less ambiguous than most in this area, the trade-offs are fewer. Yet the POHI staff have seemed to take the Farrells' desires to have Helen in the private school as a personal affront. The Farrells appreciate and respect the efforts and abilities of the POHI school staff. They just want the least restrictive, yet appropriate educational experience for their child. They don't disparage or look down on Helen's handicapped peers; in fact, they respect these children all the more because they know intimately the courage all of them have. They just consider the POHI school environment more restrictive in many ways than a regular school environment.

Parent Involvement

The Farrells, particularly Martha, have been actively involved in almost all aspects of Helen's education and therapy since the time she was diagnosed at eight months as having cerebral palsy. They have played a role in all educational placement decisions, and frequently used their rights under the law to influence decisions being made. Their full involvement has been made possible by professionals who, at a minimum, tolerated them, and in most cases welcomed their involvement. Procedures for involving them have always been present, and almost always been utilized appropriately.

III. Major Issues in the Farrell Case

The overall impact of P.L. 94-142 in the case of Helen Farrell has been positive. The major provisions of the law provided the structure for a process of evaluation and placement negotiation which, though not harmonious, has been reasonably fair and open. Without the rights spelled out in the law, Helen's parents would certainly have had less influence over the decision-making process regarding her placements, and their constant push for her to be in a less restrictive environment would have had less precedent and legal justification.

Perhaps the major issue in the case has been the institutional response of the POHI school to the least restrictive environment provision of the law. It appears that this institution's desire to have Helen participate fully (or not at all) in its program has been more powerful than any recognition of responsibility to assure the least restrictive appropriate placement for her. In a more subtle fashion, at least a few staff at that institution appear to have used their authority--in the form of control of access to therapy services--to pressure the Farrells into accepting a placement for Helen that they did not want.

An aspect of the law that remains to be tested in Helen Farrell's case is the continued responsibility of the public schools to make at least ancillary services available to handicapped children attending private schools at their parents' choice. The Director of Special Education of Helen's local district has assured the Farrells that Helen will have as equal access to special education services as every other child requiring such services, whether in private or public school. Her good intentions appear to be firm. But the same POHI school that the Farrells have chosen not to enroll Helen in next year is the institution responsible for providing services to POHI eligible children in private or regular public schools. This whole issue will be monitored as time goes on.

Helen Farrell has made remarkable progress in achieving functional mobility and physical autonomy. This is in part due to the variety of competent physicians, therapists and teachers who have worked with her; in part to her parents' love and determination that she have the best; in part to her own determination. She always has been, and remains, a happy, intelligent, active child. Academically and socially, the private, mainstreamed first grade should prove an exciting, challenging experience for her next year. A question remains, though: will she get the physical therapy that has been such a crucial part of her growth to the present, and that will remain crucial as she continues to grow and change physically?

JOSEPH EDWARDS

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I. Introduction

Brief Case Sketch

Joseph is the only child of Mary and Ernest Edwards. He was born in February 1973, and immediately diagnosed by the attending obstetrician and a team of consulting specialists as a Down's Syndrome child. After the initial shock wore off, the Edwards' set to work organizing themselves and their lives to meet Joseph's needs. They had to learn everything they would need to know: what kinds of services Joseph needed, what options were available, how to evaluate those options, how to work with professionals, what rights and responsibilities they as parents had, and what rights Joseph had, and perhaps most importantly, how to come to terms with Joseph as a handicapped child and a person. This case study is largely a description of that learning process and its effects.

Ernest and Mary Edwards are in their early thirties. A few years after Joseph was born they decided not to have any more children. Mary Edwards is tall and slim, with dark hair cut short. She projects an air of quick intensity and seriousness. Since Joseph's birth she has devoted herself to his care and education, her concern translating into a growing activism on behalf of Joseph and other families with handicapped children. She has worked with various organizations serving handicapped children and their families, has taken a course in parent advocacy, has served as a parent advocate a few times for families with handicapped children, and has run a parent's group. She has been invited to speak to students at local universities, and to professionals at local conferences. But most importantly for purposes of this study, she has thrust herself into the middle of Joseph's education, monitoring the educational process for him far more closely than most parents, even those with handicapped children.

Mary has at this point achieved an understanding, depth of perspective, and empathy that she herself acknowledges is the result of a long and painful process. Her struggle to accept the nature of Joseph's disability has been difficult. She has gone through the mourning process it is said many parents of handicapped children go through--shock and bewilderment, denial, anger, hostility, and anxiety, the beginnings of adaptation, reorganization, and finally, ongoing adjustment. Her relationships with professionals, which with some justification--as will be described--started off guarded and somewhat suspicious, have improved steadily over the years. And she has learned how to constructively "work the system" to Joseph's genuine benefit, educating herself in the law, and in the ways of the educational bureaucracy.

Ernest Edwards is also tall, glasses and a diffident manner giving him an air--confirmed in his behavior--of thoughtfulness and quiet studiousness. He has worked as a skilled engineering technician, and has recently completed a bachelor's degree in Business Administration, working and going to school

evenings. He has also been deeply committed to seeing that Joseph has the best and most appropriate education possible, and has made sure to visit Joseph's classroom and participate in evaluation and decision-making meetings. He and Mary work very effectively together as a team, each bringing different strengths, but both extremely dedicated to seeing that Joseph has an opportunity to reach his as yet undefined limits.

Joseph himself is friendly, extremely eager to enter into interactions with those about him, especially adults, and very determined to achieve academically and socially. Over the years, teachers and evaluators have constantly commented on his high level of adaptive functioning--both cognitively and socially--his desire to communicate and engage the world, and his determination. He has been somewhat constrained by limited ability in expressive language, and some gross motor awkwardness. But he has adapted well to these organic constraints, and found effective ways to communicate and participate in all kinds of activities.

The Edwards provide a stimulating, educational, and caring home environment for Joseph. Their house is full of toys, learning materials, books, and related materials for him. Martha has devoted innumerable hours to transporting Joseph to various activities. Ernest, in spite of a demanding schedule, makes sure he has time to play with Joseph at home. Both parents have reorganized their lives around Joseph's situation and needs.

A Chronology of Contacts with Institutions and Service Programs

Joseph and his parents have been involved with various programs and services for handicapped children almost continually since his birth. Mary's pregnancy with Joseph was normal. She was healthy; Joseph was carried full-term; the delivery was normal. Joseph weighed 6 lbs. 14 oz. Immediately upon examining Joseph, the attending obstetrician suspected Down's Syndrome. Ernest recalls finding out on the telephone--he had been at work. Two things came to mind--his brother, who was also retarded; and the notion of Joseph as physically deformed. Both Mary and Ernest recall that the shock of finding out was tremendous.

One of the nurses at the hospital where Joseph was born also had a Down's Syndrome child, and probably sensed what the Edwards would soon be going through. She thus asked the attending obstetrician (the Edwards' own doctor was on vacation) if she could arrange for a public health nurse to visit the Edwards at home. There was no problem, and the Edwards received their first visit when Joseph was eight days old. The public health nurse visited the Edwards periodically during those early weeks, "to see how things were going", and provide information about Joseph's needs. The Edwards were also very interested in finding out about available services for Joseph. Thus, the public health nurse contacted an Institute doing research and running programs for mentally retarded children, attached to the local university, and also the intermediate educational agency special education services division.

Joseph and his parents began participating in the early intervention program of this Institute when Joseph was 12 weeks old. The program consisted of home visits by professionals to share information about Joseph's needs and demonstrate activities to enhance his development, some center-based activities for Joseph, and monthly parent meetings at the Institute. Ernest recalls, with some chagrin, the early home visits:

> "...the folks who were coming made us feel incompetent; ...they suddenly showed up one day, we didn't know why they were visiting...suddenly, here are these people coming into your home, telling you what to do with your child; also, they weren't truthful with us on some things...we were told we had to see a social worker to get services through the program for Joseph, that it was part of the requirements for everyone participating ...through records we later acquired we found out that this was not the case, they felt that we needed help..."

The Edwards had a more positive experience with the monthly parent meetings. Aside from the information shared, these meetings led to the formation of a parent support group, which Mary chaired from its inception to early 1979, and in which both Mary and Ernest have remained active. The opportunity to share feelings, experiences, advice and information has been very valuable for parents involved. Participation in the early intervention program also helped stimulate the Edwards' concern for Joseph's cognitive development, which in turn led to their efforts to learn as much as they could about this area of human development.

The public health nurse also connected the Edwards up with the special education program of the intermediate education agency serving the county in which they lived. This led to some information gathering on the part of agency staff, and to the first Educational Planning and Placement Committee (EPPC) meeting for Joseph, which took place in October 1973, nine months after Joseph's birth. The special education staff participating in this meeting recommended to the Edwards that Joseph participate either in the day training center program, a day care center program for handicapped children, part of the county's Mental Retardation Service Center, or a day program for multiply handicapped children. They were also offered occupational therapy consultation, speech therapy, and social worker services. The Edwards decided to visit the two center-based programs and then select one for Joseph. They would also continue in the Institute early intervention program.

They chose the day training center program, and Joseph was enrolled for two days a week. But by November, the Edwards had decided to withdraw him from that program. In a letter to the Mental Retardation Service Center director, the Edwards wrote that scheduling and transportation conflicts were forcing them to withdraw Joseph from the program. As they now recall, the more basic reasons were their satisfaction with the home visit program, their

feeling that Joseph was functioning at a higher level than the other, older children in the program, and the general feeling that two days a week in a relatively unstimulating setting would not do much for their child. This was the first manifestation of the activism that would characterize their behavior with respect to the school system in future years. They report not being aware of any laws to protect them or Joseph at the time, but being clearly aware of their rights as parents.

Joseph and his parents continued participating in the university Institute's early intervention program during the 1973-74 and 1974-75 school years. Reports and evaluations from that period indicate steady development in Joseph in most areas, with continued lags in language and gross motor abilities. He is reported as high functioning, active, and very adaptive. These same reports suggest growth in the Edwards--in continually improving relationships with professionals, in their knowledge of and persistent interest in child development, and in designing strategies to meet Joseph's needs.

By the fall of 1975 there were indications that the university Institute's early intervention program was going to run out of funding by the end of that academic year. During the fall of 1975, program staff had been visiting a number of preschool programs in the area, and had begun compiling a record of them for program parents. The Edwards' home visitor recommended that the Edwards look at the preschool program of a local educational research center that had just received a grant to develop an integrated program for handicapped and non-handicapped children. The grant enabled the center to cover the costs of participation for handicapped children. Joseph began attending that preschool program in February 1976; at the same time he and his parents gradually decreased their involvement with the Institute's early intervention program.

In December 1975, the Edwards brought Joseph to the Speech and Hearing Clinic of another local university. They were concerned that his speech development was slow. Joseph was evaluated by the clinic staff, and a speech therapy program was recommended for him, which he began in May of 1976. The therapy combined group sessions and individual sessions, for a total of six hours a week. Both of Joseph's programs were private, and the Edwards handled transportation.

In May 1976, the special education division of Joseph's school district recommended and conducted a second EPPC meeting for Joseph. Staff from all his present programs, as well as the Edwards, were present. Summer and fall options were discussed, and the special education division staff present recommended that the Edwards consider placement for Joseph in a public school preschool program for handicapped children. Also reviewed at the meeting was a report from an evaluation conducted by the public schools' center for trainable mentally impaired. The report stated that placement for Joseph in a trainable mentally impaired program was inappropriate, and that it was "important for Joseph to be in a program that will help him to maintain his present level of functioning, and learn new skills."

The Edwards wanted time to visit the public preschool program for handicapped children (mostly educable mentally impaired and emotionally impaired), and a placement decision was deferred until June. Another EPPC meeting was held in June, at which time the Edwards indicated that they preferred to maintain the ongoing arrangement for Joseph--the speech therapy program mornings and the private integrated preschool program afternoons. The Edwards' preference was approved for the 1976-77 school year, with the school district paying for speech therapy at the college clinic, but not providing transportation because of scheduling difficulties.

The two programs in which Joseph participated during the 1976-77 school year were significantly different in philosophy, expectations of Joseph, and atmosphere. While this caused some stress for Joseph--he functioned much more effectively when structure and expectations of him were consistent--reports indicate that he made steady progress and enjoyed participating in both programs. Progress was particularly notable in aspects of cognitive development not dependent on expressive language, in independent behavior, and in appropriateness of social interactions.

In June 1977, a psychological evaluation was conducted by a public school psychologist, at the Edwards' request, to help determine the most appropriate placement for Joseph for the 1977-78 school year. Possibly because the Edwards didn't request one, no formal review of Joseph's placement was conducted. The evaluation found Joseph to be functioning still in the educable mentally impaired range, with speech continuing to be a critical problem. A recommendation was made that his placement for the 1976-77 school year be continued for another year.

The same placement and services were in fact continued the following year. Joseph continued to profit from both programs, but some concern was voiced by the staff of the speech clinic that Joseph could use a more structured educational program than the private preschool program, one that demanded more expressive language. The private preschool program staff report that Mary and Ernest Edwards were very active parents--visiting the classroom frequently, asking advice and offering suggestions about how to more effectively meet Joseph's needs. As one teacher there noted: "they demand more support than most parents we work with, which is both rewarding and frustrating." That program also had a home visiting component, and home visitors were consistently impressed with the stimulating home environment the Edwards had created for Joseph.

In March 1978, the Edwards requested a comprehensive evaluation for Joseph from the university Institute that had served them from 1973 to 1976 through its early intervention program. They requested the evaluation because they wanted documentation to justify enrolling him in the local school district's developmental kindergarten (for educable mentally impaired and emotionally impaired) in the fall. Although this was an independent evaluation, paid for by them, they knew that they had the right to have this, as well as public school reports, considered at EPPC meetings. They anticipated an

EPPC meeting in May or June, and wanted to prepare as much evidence as possible supporting their placement desires. Also, they had experienced what they perceived as an inadequate evaluation of Joseph by the school district in 1977--focusing too much on I.Q.--and they felt a more comprehensive evaluation would more accurately reflect Joseph's abilities.

In May of 1978--Joseph was now five years old--a fourth EPPC meeting was held. The independent evaluation findings were in fact presented at the meeting, and became the basis for Joseph's recommended placement. The findings indicated that Joseph's main problems continued to be in the areas of language development and gross motor development; that Joseph would have trouble functioning in a regular kindergarten--he needs both alot of structure and individual attention--but that the private integrated preschool program was no longer appropriate; that his performance seemed to be frequently below his capabilities; and that "his parents have spent much time in teaching Joseph, and the (positive) results of cognitive testing show this."

Based on these findings, and reports from his teachers and therapists, it was recommended that Joseph be enrolled in the fall in the above-mentioned developmental kindergarten, and that he receive regular speech therapy in the school setting. The Edwards agreed with both these recommendations, feeling that they had received exactly the recommendations they wanted from the committee.

The Edwards' preparations for this EPPC meeting began to reveal a pattern that has since been observed in later EPPCs. The Edwards have learned how to use the evaluation and decision-making process mandated in P.L. 94-142 to assure placements that they feel are most appropriate for Joseph. They use independent evaluations, for example, to justify changes or continuation in placements. They seek out professionals to assure that the latter are aware that they, the parents, have strong preferences for Joseph. This creates a climate where it is expected that the Edwards will have a clear, justifiable opinion when decisions are to be made. While their activism has led to strained relations with professionals at times, it has also led to placements for Joseph where he could grow cognitively and socially to his maximum potential.

The first public school Individualized Educational Program (IEP) was developed for Joseph in September 1978.[1] (The speech clinic had developed one the previous year, and the private preschool did individualized planning for all children.) The Edwards were not present, but were consulted by phone and through contacts with Joseph's teacher. Annual goals for the overall IEP were given as "language and cognitive development; listening and fine-motor skills." Objectives were identified only by the phrase "as specified in the EMI curriculum guide." This first IEP was not very

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[1]As has been mentioned in other case reports, in Michigan the EPPC is the setting for major program decision making and planning, the IEP for more detailed goal setting.

detailed, and future ones--in June and December 1979--were just as telegraphic. It appears that the EMI curriculum guide serves in that setting as the IEP for the classroom program for most retarded children considered, like Joseph, to be in the educable range. (Joseph's speech IEPs have always been alot more detailed.)

Joseph adjusted slowly but steadily to the new environment and its demands. There were many transitions during his half-day program, and these were very stressful to him. Also, he had always learned behavioral expectation from observation of those around him--through modeling and imitation. His handicapped peers reportedly were not serving as appropriate role models for him. Thus, he was picking up what his parents felt was socially very inappropriate behavior. Speech therapy was also, reportedly, difficult for Joseph. But all reports from that time indicate that he tried very hard to meet expectations.

In February 1979, a public school re-evaluation of Joseph's cognitive functioning was conducted by a psychologist serving the school Joseph attended. The report from that evaluation indicated that, at age 6-1, Joseph's developmental level was generally about three years; his I.Q. was in the upper trainable mentally impaired range; that he had a short attention span, and was moody. The psychologist recommended re-evaluation for the county's trainable mentally impaired center, although one more year in the EMI kindergarten was appropriate. The Edwards were very upset by the findings.

Partially in response to the findings, the Edwards had another independent evaluation of Joseph done in May 1979, this evaluation using a developmental assessment battery. In direct response to the findings they wrote a letter to the school district, to be inserted in Joseph's records. They pointed out that Joseph had demonstrated he could perform certain tasks and had manifested cognitive abilities not demonstrated in the testing. They pointed out that they were aware that Joseph sometimes doesn't perform up to his capability in testing situations, and they believed that was the case in the February testing. The independent evaluation, conducted by an occupational therapist at the college where the speech clinic was housed, recommended continued consideration for EMI placement. A third evaluation, conducted by the public schools trainable mentally impaired center staff, recommended the same, noting that Joseph was functioning in the educable range, and that he was a high functioning Down's Syndrome child. These evaluations, and the Edwards' dissatisfaction with Joseph's school experience that year, set the stage for his next EPPC.

Joseph's fifth EPPC meeting was held in May 1979, when he was six years old. The Edwards brought an advocate from the local Association for Retarded Citizens; the school district's Director of Special Education participated; the principal and staff of the school housing Joseph's developmental kindergarten participated. The first part of the meeting was devoted to a review of Joseph's progress, and a report of evaluation findings. His classroom teacher and speech therapist noted uneven progress in Joseph that year, with continuing problems in appropriateness of behavior in school, and in expressive language development. The two evaluators reviewed their discrepant findings,

and then engaged in a long argument about why their findings were so different. The psychologist who had done the February evaluation that had so upset the Edwards kept insisting on the accuracy and true representativeness of the lower scores he had found for Joseph. The trainable mentally impaired center psychologist argued that, while he agreed that Joseph's performance was uneven, "I believe that if he can achieve the higher score (at least some of the time) we ought to give him the benefit of the doubt."

At that point, the meeting moved on to a discussion of the options for Joseph for the 1979-80 school year. These included another year in the EMI developmental kindergarten, regular kindergarten with teacher consultant services, just regular kindergarten, a self-contained special education first-grade classroom, and regular first-grade with teacher consultant services. All options included continued speech therapy. Mary Edwards was asked her preference and said that she would prefer regular kindergarten with teacher consultant services. She felt Joseph wasn't making progress in or enjoying the developmental kindergarten; that he needed normal children for more appropriate and positive behavior modeling; and that she didn't want him to spend so much time playing next year.

The principal noted at that point that he would prefer a gradual transition to a mainstreamed classroom for Joseph. He felt an abrupt change would be "too big a step," too overwhelming for Joseph. Since Joseph adapted slowly, he could be started out in selected activities such as art, gym, music. The teacher consultant who would be the one to work with Joseph said that from what she had heard she couldn't decide whether or not Joseph would profit from the change to a regular kindergarten; but it was clear he needed to develop work-study habits.

Mary Edwards pointed out again that Joseph learned mainly by modeling, and she wanted normal peer models for him. She asked for clarification on how long the transition would take, and whether a plan would be developed. The principal assured her that the transition would take place when and as appropriate during the fall, and that a concrete plan would be developed.

The 1979-80 year started with Joseph in the developmental kindergarten once again, receiving also regular, individual speech therapy. At the end of September the Edwards went in to talk to the principal about plans for Joseph's transition to regular kindergarten. He reportedly gave them the impression that the transition process would begin in "a couple of weeks." Late in October, Mary Edwards came in to observe Joseph, and the teacher of the developmental kindergarten told her that the principal had no intention of totally moving Joseph to a regular classroom; at most it would just be for selected activities. Mary returned home extremely upset. She went over the minutes of the May EPPC, and it appeared to her that by that point--the end of October--there should have been a plan for Joseph's transition; also, that the extent of Joseph's mainstreaming was to be left open according to the plan.

At the end of October the Edwards met with the principal again, at their request. During the meeting it became clear that his and their interpretation of the EPPC recommendations were clearly different. While to the Edwards it was clear that Joseph would eventually be participating fully in a regular kindergarten that year, to the principal this was not at all clear. He suggested another EPPC, to be held in two days. There was no reason given for such a short turn-around time. Nonetheless, the Edwards agreed, and also managed to find an advocate to accompany them.

The EPPC meeting occurred at the beginning of November. The principal acknowledged that, regardless of differences in interpretation of the last EPPC's recommendations, the school should have developed a plan for Joseph and begun implementing it. But there were enrollment problems at the school, preventing the selection of an appropriate kindergarten for Joseph. At that point a discussion took place concerning the wisdom of a gradual, open-ended transition from self-contained special education to regular kindergarten. Two participants invited by the Edwards--both former teachers of Joseph with special education backrounds--argued in detail and convincingly that a gradual process of mainstreaming Joseph in increasing increments over time was not appropriate and possibly harmful to him. It was agreed that he functioned best when expedtations were consistent, structure was clear, and simple, and when his day did not have too many transitions. To put him in a "transition" state for too long a time would be harmful to his educational progress. Mary Edwards' main concern was to get Joseph out of the developmental kindergarten as soon as possible. The school staff did not at this meeting express any disagreement with the Edwards' desires.

As a result of the discussions, a clear and unambiguous recommendation was arrived at that self-contained special education classroom services would be terminated, and placement in a regular kindergarten with teacher consultant services would be implemented, within three weeks. November 26 was set as the last day the change could be made.

By the end of November, a kindergarten had been selected for Joseph to attend, but sickness first on his part, then on the teacher's part, prevented him from joining that class until January. The class and teacher selected for Joseph were the Edwards' first choice, and they were very satisfied. (They wanted a teacher who was warm, but who was also authoritative, and could set clear limits.) This teacher reports that when Joseph arrived in her class she knew very little about him. She had no IEP for him, and was not aware of any that had been developed. In short, she felt unprepared for him. Nonetheless, she understood her goals for him to be mainly socialization; that is, the inculcation and enhancement of age appropriate social behavior. Academically, she saw herself to be "in a holding pattern," with him. He needed a lot of individual attention and guidance that she simply had not time to give him; and, she said that she didn't know anything about special needs children.

In observations of Joseph in that classroom situation, it appeared that this teacher was handling him excellently, setting limits, yet being supportive and warm, treating him as a person first. While Joseph was learning a little--mostly through imitation of other children--he wasn't getting the individual attention with cognitive tasks that he needed. He was nonetheless very happy and very engaged. (The class has a part-time aide and student teacher who were able to work with Joseph.)

Soon after Joseph began attending this kindergarten--still for one-half day each day--his teacher and the Edwards decided that it would be too disruptive to his adjustment to be taken out of the room for teacher consultant services, especially as his speech therapy was continuing, and he regularly left the room for that. Thus, during the January to June period Joseph did not participate in the teacher consultant program that he was eligible for. This undoubtedly affected his academic progress. But, it became clear as the year progressed that the Edwards' main goals were to enhance Joseph's social behavior and work habits, to make those behaviors and habits more age appropriate. (To facilitate this process they had enrolled Joseph in a preschool center, a few mornings a week so he could get all of his playing--still necessary for him--done, and be more prepared to work in the afternoon.)

In fact, Joseph's months in the regular kindergarten were very positive. His parents and teacher report a lot of improvement in his behavior, an increase in autonomy, age appropriate behavior, and social interaction skills. His lack of expressive language continued to prove extremely frustrating to him. But he was communicating on his own quite effectively. The change in him after he left the developmental kindergarten was reported and observed to be marked. Much of this change was apparently due to a remarkable teacher who expected Joseph to be competent and to exhibit appropriate behavior.

As June approached, the Edwards began preparing for what they were aware was going to be a major transition point for Joseph--entrance into first grade. Kindergarten was not appropriate for him anymore--he was too old and big, and he was not profiting from it academically. The question was what kind of first grade would provide the most profitable and appropriate experience for him. They looked at the elementary program of the private educational research center where he had had such a positive preschool experience. They observed at a couple of the elementary schools that were likely placements for him. One thing was clear to them, they did not want Joseph in a special education self-contained primary classroom, and they probably didn't want a shared-time program. Joseph's experiences in the special education kindergarten had closed their minds to those options.

Joseph's seventh EPPC meeting was held in late May 1980. He was seven years old. In attendance were the district coordinator of special education, an advocate, the principal and key staff from Joseph's current school, a psychologist from the school he would likely attend, the Edwards, and a former teacher from the private integrated preschool program. Once

again, Joseph's progress was reviewed. His improved social behavior was described, his academic frustrations and achievements, and his continued slow language development. The psychologist asked if, in the opinion of those working with Joseph, he was still developing cognitively. It was left as a question at that point.

Options for placement for the 1980-81 school year were then discussed. It was agreed that special education or regular kindergarten was no longer appropriate, because of Joseph's age. The main options emerging were regular first grade with teacher-consultant services, or a self-contained EMI primary classroom. Both would include continued speech. The principal of Joseph's current school once again expressed his reservations about mainstreaming Joseph. "Given the evidence," he said, "a self-contained primary EMI room is most appropriate." He was thinking in terms of Joseph's academic needs. His speech therapist, teacher consultant, and the special education coordinator agreed. His regular kindergarten teacher said she hadn't made up her mind yet what was best for him. (It was brave of her to dissent from her colleagues; this writer has not seen that happen often.) His former teacher from the private preschool wanted to know more about what each option would be like--"it depends on the attitude of the teacher and composition of the class," she felt.

The psychologists then asked the Edwards to argue their case:

> "I know you don't want a self-contained special education class for Joseph; I want you to explain why. Traditionally, a child functioning like Joseph would be in a self-contained class; in a first grade with 28 kids in it, containing a wide developmental range, a teacher has alot to do already---nonetheless, it has been done, we do have a couple of kids like Joseph mainstreamed in the district..."

Mary Edwards said that they preferred a regular first grade for Joseph, with teacher consultant services. She said they'd seen alot of progress in Joseph since he switched to the regular kindergarten. "He has always been uncomfortable with special needs peers, and expectations of him were lower" in the special education class. She and Ernest had worked very hard to have Joseph's behavior as close to age-appropriate as possible, and they didn't want to lose those gains. She felt, also, that it would "just be a step backward for him to go to a self-contained classroom again." Finally, she said that he may fail in academics, but they wanted him to have a chance to try. "If I felt he was uncomfortable I'd be the first to take him out," she concluded.

Ernest Edwards, who, as usual, had been largely silent the whole meeting, then summed up their feelings:

"...if he fails, then he's had the opportunity to try and fail; but we have to give him the opportunity to fail at the highest level; that's the most we as parents can strive for..."

Various reservations continued to be raised, as the Edwards made their case; but clearly they were going to have their preference accepted. It was asked why Joseph hadn't used teacher consultant services. Mary explained and then said that the disruption of having Joseph pulled out of class was a lot less within a full-day program, such as the regular first grade would be. A shared-time (half-day special education, half-day regular education) program was offered as a possibility. The Edwards did not want the discrepancy in expectations. Finally, it was agreed that Joseph's placement would be regular first grade at his local elementary school, with eligibility for maximum teacher consultant services (actual services to be worked out), and no less than one hour a week of speech therapy. An IEP would be developed in September, based on this placement, and reviewed ten weeks into the year to see how things were going for Joseph. The committee wanted to keep all possibilities open for him.

II. The Edwards Case and the Five Provisions of the Law

Protection in Evaluation Procedures

Joseph Edwards has had regular and thorough evaluations since the time of his first EPPC at age nine months. Evaluations have been conducted by almost all the institutions that have provided service to Joseph, and certainly by all the major institutions. The Edwards have always been informed of upcoming evaluations, have always seen the results, and usually had an opportunity to discuss those results. The available evidence indicates that evaluators have been appropriately trained, have made an effort to create a comfortable climate, and have selected age-appropriate instruments and techniques. Finally, evaluations conducted have been used to help arrive at placement decisions.

Yet evaluation has been a problematic issue in Joseph's case, due primarily to the Edwards' feelings that too much emphasis has been placed on I.Q. scores, and that standardized instruments do not adequately reflect Joseph's functional abilities. The Edwards' dissatisfaction with standardized measures that provide primarily quantitative scores of potential and ability have led to their arranging for independent evaluations for Joseph on three occasions, all before important placement decisions were to be made. In a related fashion, the Edwards' have always tried to have placement decisions reflect not only what Joseph can't do, but what he can do. Thus, they have attempted to make sure that his day-to-day functional abilities are described in placement meetings and through evaluation documents such as school reports and observation records. On one occasion they have asked to have an evaluation report amended to more accurately reflect Joseph's abilities.

Joseph's first independent evaluation was conducted by the university Institute that had provided the early intervention program for him, and was far more comprehensive than a school psychologist's report would have been. (They knew this from experience--a prior school psychologist's report in 1977.) Joseph was evaluated by a team that included psychologists, special educators, occupational and physical therapists, and a nutritionist. The findings included descriptive data on Joseph's functional ability in a number of areas, as well as practical recommendations for programming. The information from this evaluation did in fact form the basis for the placement decision made at an EPPC meeting soon after.

His second and third independent evaluations were arranged for in response to the February 1979 evaluation by the school psychologist, which offered a very pessimistic appraisal of Joseph's intellectual potential and abilities. One of these was conducted at no cost to the Edwards by the county's trainable mentally impaired center. As has been noted, findings from this evaluation indicated that while Joseph's performance was erratic, his potential and abilities were still in the educable range, and that since he was a high functioning child, he should be given the benefit of the doubt

when there were any questions. The second of these two evaluations was a development assessment, conducted by an occupational therapist at the college where Joseph had had speech therapy. It also presented a more optimistic appraisal than the February evaluation. Both of these independent evaluations were considered and used during Joseph's spring 1979 EPPC meeting.

The Edwards have also insisted, when they felt it was necessary, on adding amendments to Joseph's evaluation records. In the February 1979 evaluation by the school psychologist, for instance, they indignantly refuted a finding that Joseph could not recognize letters or most numbers by writing a letter, to be included in his records, and by requesting that school reports contradicting this finding be placed in the records. Both the letter and the reports were considered during that spring's EPPC, along with the February evaluation.

The Edwards, on behalf of Joseph, have thus clearly taken advantage of and benefited from the protection in evaluation provisions of P.L. 94-142. They have insisted that evaluation data used for placement decisions reflect more than I.Q., and include Joseph's abilities as well as his disabilities. They have used independent evaluations to broaden the basis for judgment about placement decisions. Without their efforts and this protection it is possible that Joseph would by now have been placed in the county's trainable mentally impaired center, cutting off his opportunity, as Ernest Edwards has stated it, to try, and perhaps fail, but if so, fail at the highest level.

Procedural Safeguards

The procedural safeguards provision of P.L. 94-142 has generally had a positive impact on the evaluation, placement, and programming process for Joseph. A regular, clear-cut process, known to the Edwards, has always been followed. They have generally known how to protest, contribute, and otherwise shape that process (due to their own research into their rights, and to consultation with advocates). They've received written notification of meetings well in advance, except in the one instance in November 1979. Assurance of the Edwards' availability to participate in such meetings has been sought. The Edwards have had access to and received upon request all materials in Joseph's records. They have been able to request amendments and have successfully had records amended at least once (unsuccessfully at least once). And they have had and used their right to independent evaluations for Joseph.

The local educational agency involved has generally been very sensitive to the Edwards' concerns and desires regarding Joseph. The Edwards have always been able to bring anyone they wished to EPPC and other meetings. Also, in the one instance in which they were upset about an ongoing placement, they were able to have an EPPC meeting arranged promptly (almost too promptly), and were able to have Joseph's placement modified. The Edwards have never had to resort to threat of or actually begin due process proceedings.

Mary and Ernest Edwards have come to be exceptionally aware of their rights under P.L. 94-142 and Michigan's state law for handicapped children. They have shown skill and judgment in using these rights to assure what they have seen as the most appropriate education for Joseph. As one teacher of Joseph has noted, their concern for and activism on behalf of Joseph has been both frustrating and rewarding to professionals involved in providing him an education.

Individualized Educational Program

In his early years, programs for Joseph were clearly individualized, and planned to meet his and his parents' needs. This appears to be the case for the early intervention program of the university Institute, and the private integrated preschool program. But in the last two years, there is some question about how truly individualized Joseph's program has been in the self-contained special education kindergarten, and then the regular kindergarten. While the letter of the law has always been observed for Joseph, it is not clear that the intent of the law has been.

In general, Joseph has had IEPs developed for him every year, usually in the early fall. Meetings to develop his IEP have not always included the Edwards, but this is in part due to Michigan's two-step system of EPPC and then IEP. Nonetheless, the Edwards have always had input into the formulation of goals for Joseph, at least on the phone or in informal meetings, if not in formal IEP meetings. In the last two years there have been IEP review meetings in the spring, and the Edwards have reportedly attended these as well. Also, IEPs have always been developed for speech therapy, as well as for Joseph's classroom program.

A question, nonetheless, arises when the content and implementation of Joseph's IEP is examined. First, with respect to performance objectives, the last two IEPs, both for Joseph's kindergarten programs, have included only the statement "as specified in the EMI curriculum guide." Mary Edwards recalls that some specific objectives for Joseph were discussed; but they are not described in the plan itself. The IEP has not reflected, in Joseph's case, specific objectives for him, based on his unique abilities and needs. Rather it has reflected an intention to use a standardized curriculum guide designed for children functioning within a fairly wide range of abilities, and whose handicapping conditions may be different in nature. Also, without specific objectives designed for Joseph in the fall, it has been difficult to maintain an individualized program during the year, and measure Joseph's progress in that program in the spring.

With respect to Joseph's actual program, observations and interviews suggest that his classroom experience during at least the last year has been based more on group activities than on individualized activities. Joseph's regular kindergarten teacher, in particular, reported that she had not seen Joseph's IEP. She formulated her own goals for him, based on

conversations with Joseph's mother. These were primarily social in nature. Joseph's academic program was basically identical to that of his non-handicapped classmates, with his teacher helping and guiding him as she had time. Due at least in part to a lack of an appropriate IEP for Joseph's classroom program, his academic progress has been limited this past year, in spite of efforts by his teacher to work on areas the Edwards feel are important.

Least Restrictive Environment

As in a number of other cases in the study, this provision of P.L. 94-142 has proven difficult to interpret and reach agreement on in Joseph's case. Consensus on the definition of least restrictive appropriate environment in Joseph's case has been extremely difficult to reach. His parents have generally argued that the least restrictive environment in which he could still function and feel comfortable socially was the best environment for him. They have felt that he learns primarily by modeling and imitation; thus, they want him to have peer models with age-appropriate behavior and abilities. The Edwards have rejected the position of almost all public school staff who have worked with Joseph--that academically he would profit most from a self-contained special education classroom--because when he was in a self-contained special education classroom during the 1978-79 year, he didn't function well at all.

It appears that that one negative experience has hardened the Edwards' resistance to special education classrooms, although they are aware that in the near future Joseph will begin to fall dramatically behind his age-mates in academic ability. His lack of expressive language will also continue to grow as a factor in consideration of most appropriate placement: active learning, learning by manipulation of materials, decreases steadily in the public schools as children grow older. Regardless of Joseph's particular negative experience with self-contained special education, the Edwards have generally been less conservative, and the school system more conservative in defining appropriate placements for Joseph.

A number of strategies have been used by both the Edwards and the schools in negotiating placement for Joseph. When Joseph was younger, the Edwards simply withdrew him from public school programs--this was first done when he was less than a year old--and found what they considered to be appropriate private placements for him. Both the Edwards and the schools have used evaluations as the basis for arguing placement. The schools have always left placement decisions open for review some weeks into the school year. (This has benefited the Edwards at least once.) The schools have used Joseph's medically defined handicap--his being a Down's Syndrome child--as part of their argument for defining particular placements. The stereotypic view prevalent in much of the literature that Down's Syndrome children are usually not "educable" has certainly contributed to a lowering of expectations for Joseph on the parts of school

psychologists and special educators. (In at least a few instances, evaluators have noted surprise in finding Joseph to be so "high functioning".)

The Edwards have always worked hard with Joseph at home, to enhance his performance on school-related tasks; and knowledge of that fact has led at least one evaluator to question the reliability of his findings. Problems in evaluating the ability of a basically non-verbal child have also been present at times. Joseph's scores on multi-faceted test batteries have also been variable enough to make interpretation concerning his level of functioning difficult. To this point, professionals involved have been persuaded to give Joseph the benefit of the doubt. It is not clear that this will be the case in the future.

In spite of differences in opinion, the local educational agency serving Joseph has been generally sensitive and responsive to the Edwards' desires. His placement has always reflected their wishes, and never have any of the educators or testers involved consciously sought to undermine placement decisions. The school districts' openness to the Edwards' wishes, combined with their own determination that Joseph be educated to the extent possible with non-handicapped peers, has led to positive impact in Joseph's case for this provision of P.L. 94-142.

Parent Involvement

The impact of this provision of P.L. 94-142 in the Edwards' case has been amply illustrated in discussion of the above provisions. Mary and Ernest Edwards have been consistently and significantly involved in identification, referral, evaluation, placement, and educational program determinations for Joseph. This involvement appears to have had a decided impact on decisions made concerning Joseph's placement. Both private and public institutions serving Joseph and the Edwards have made considerable efforts to accommodate the Edwards' activism, even when that activism seemed to the professionals involved misplaced or overbearing. That activism was recognized as the Edwards' right and responsibility.

The Edwards' involvement with Joseph's special needs has come at no little cost to them. They have devoted their leisure time to meetings and support groups, to observing Joseph in school, to talking with teachers, to preparing for meetings, to transporting Joseph from setting to setting, and to acting as advocates (in Mary's case) for other parents. They have learned all they could about Joseph's cognitive and social needs. Finally, they have devoted enormous emotional energy to seeking appropriate services for Joseph. Their lives--particularly Mary's--have revolved around meeting Joseph's needs. P.L. 94-142 has provided a vehicle for first releasing and then channeling the considerable energy and commitment manifested by the Edwards on Joseph's behalf.

III. Major Issues in the Edwards' Case

The overall impact of P.L. 94-142 has been positive in the Edwards' case, both from the perspective of Joseph and his parents, and from the perspective of various institutions involved in serving Joseph. The law has provided a framework for negotiations, and a basis for mutual understanding of rights and responsibilities among all involved. Interpretation of the law has proven to be problemmatic with respect to defining least restrictive appropriate environment. But interpretation of this provision has been worked and re-worked within a consistent framework.

In the last two EPPCs the Edwards have successfully argued for placement of Joseph in a less restrictive classroom environment, yet they have done so seemingly at the expense of academic progress for Joseph. His regular classroom teacher this past year simply was not prepared--through training, classroom materials, and prior experience--to meet his academic needs. The decision not to use teacher-consultant services further limited Joseph's academic program. Whether the likely social gains of placement next year in a regular first grade classroom can be complemented by academic progress remains to be seen. Both the Edwards and the other participants at Joseph's May 1980 EPPC agreed on one thing: more important than the fact that a classroom is special education or regular education by name is the climate created by the teacher through her expectations for and attitudes toward the special needs child.

Joseph's participation in the university Institute's early intervention program, and later in the integrated preschool program of the private educational research foundation, appear to have enhanced his functional abilities, and, inconsistently, his performance on standardized tests. Equally as important, the Edwards' early contacts with educational programs for Joseph enabled them to gain useful child development knowledge and practical ability to influence institutional decisions, both of which were later employed in contacts with the public school system. As Joseph enters first grade the Edwards are quite sophisticated in "working the system" to assure their desired placement for Joseph. The school system has responded by keeping placement a fluid thing, always leaving open the possibility of changes if Joseph is uncomfortable in or not profiting from a particular program.

The Edwards' continue to have high expectations for Joseph. They are aware that increasingly difficult years lie ahead for him in an academic sense. At some point, it appears that he will have to begin participating more fully in a self-contained special education program. But before expectations for him begin to be defined even more by his handicapping condition, they want Joseph to have an opportunity to strive for the highest level of cognitive and social functioning that he can achieve. They will continue to use P.L. 94-142 as a vehicle to assure this opportunity.

BARRY MARSHALL

I. Introduction

Brief Case Sketch

Barry Marshall was born in July, 1969 to Judy and Ronald Marshall. At birth, Barry was diagnosed as having hypertelorism, low-set ears, undescended testicles, hand anomalies, deficiency of the scalp tissue in two areas, and swallowing problems. In addition, during his first month of life he experienced several periods of time when he would turn blue for a few seconds. From birth on through the following years, Barry was in and out of hospitals several times undergoing surgeries and evaluations. His physical anomolies were accompanied by other problems (e.g., speech) which eventually showed up during the many evaluations he received over time, and has had the greatest impact on his educational placements.

Barry's family is close-knit and affectionate. His parents are both 36 years old and he has a brother, Jerry, who is fourteen years old. His maternal grandparents live next door to the Marshalls. Since the Marshalls live in a semi-rural area, Barry has lots of outdoor space to play in. Judy Marshall takes care of three younger children on a regular basis (a preschooler, toddler and infant) and displays the same affectionate concern and relaxed temperament with them as she does with her own children. The whole family, as well as the preschoolers, are learning signing in order to communicate more effectively with Barry.

Today, Barry Marshall is an active, friendly ten year old who uses signing along with some verbal expression as his means of communication. He enjoys swimming, sports and riding his bike. He has a well-developed sense of humor, laughs easily, and enjoys playing games with adults. He is attending a local public school and has been placed in a self-contained classroom. His mother reports that he is being mainstreamed in art, music and gym, but she is not happy with this arrangement. Her feelings about Barry's placement are discussed in later sections of this report.

Chronology of Contacts with Institutions and Service Programs

At six months of age, Barry was admitted by his family to a large hospital in a city near his home to be treated for a suspected case of meningitis. Although meningitis proved not to be the source of his illness, Barry was retained at the hospital for further testing in relation to his congenital anomalies. When he was released, the Marshalls were advised that their son should be evaluated and treated by several departments within the hospital during the coming year. But, although the advice was given, no specific appointments were scheduled and no information was provided to the parents as to which department(s) would be contacting them or should be contacted by them.

Therefore, the next contact with the hospital occurred in 1971 when Mrs. Marshall became concerned about Barry's eyes upon noticing a film that seemed

to cover the eyeballs. While Barry was undergoing eye surgery at the hospital, Mrs. Marshall inquired further about possible treatment for Barry by departments with the hospital.

At this point, Mrs. Marshall was referred to the resident psychologist who started the numerous evaluations of Barry. Over the years since he was born, Barry has been examined by over 90 professionals in over 20 institutions. He has undergone three surgeries for the undescended testicles as well as eye surgery. He continues to be followed by the hospital's eye clinic and the dental clinic and oral surgery is planned within the next year or two.

At this writing, Barry has had nine Educational Planning and Placement Committee (EPPC) meetings, and there have been three hearings in connection with two placement decisions. He is currently multiply diagnosed as Learning Disabled, Educable Mentally Impaired and Physically or Otherwise Health Impaired; how this situation came about is described below. Treatment at present concentrates heavily on speech therapy, with signing a more recent addition, with the aim of improving Barry's communicative skills.

The EPPC process was started for the Marshalls with the implementation of the state's mandatory Special Education Act of 1973. They received a letter from the director of the special education center in a neighboring intermediate school district where Barry was receiving services at the preschool level. This letter stated that, due to implementation of the law, Barry could no longer be enrolled automatically in their program. The letter made it clear that Barry now became the responsibility of his own local or intermediate school district and that those officials would have to provide special education services. While nothing was mentioned in this letter concerning the "process" required under the law, the parents were informed that they must personally request special education services from their own school district.

Due to lack of appropriate programs in Barry's own local and county schools, however, Barry was placed (by EPPC decision) back in the neighboring intermediate school district's special education preschool classroom. In January of 1974 when the first EPPC was held, placement was based on the evaluations of that district's psychologist. To quote his evaluation report of Barry at age four years, four months: "His expressive language is markedly retarded and accounts for the major deficits--in vocabulary, expressive language per se, and his ability to indicate comprehension of spoken language and language-mediated problems. The gap between his receptive and expressive language is very wide, and may represent a potential for substantial gains if he learns to use expressive language, or significant loss as he becomes older, if he is unable to use abstract language. It is on the question of language development that future educational planning must be based."

Barry's second EPPC was held at his local intermediate school district and is indicative of the ongoing problems involved in his placements. The meeting was held in July 1974, when Barry was five years old. The following major issues regarding Barry's evaluation and placement were identified at this meeting:

Evaluation

- Language development is a major problem for Barry and intensive therapy is recommended for five days each week.
- Barry is able to follow directions and to carry out simple tasks.
- Barry needs more stimulation.
- Physical involvement does not limit Barry.

Realities for placement

- No distinct preschool program is available for educable children in Barry's county.
- The special education director suggested as a possibility for an in-county placement, a kindergarten setting with intensive supportive help from the intermediate office because such a program would (a) offer modeling and (b) avoid busing. The director stated that Barry was the only preschool educable mentally impaired child known in the county. The local school principal stated that there were 25-30 children in kindergarten and he was apprehensive about Barry going into this regular classroom where readiness for first grade is primarily stressed. He agreed that a preschool educable mentally impaired program would be ideal and that Barry needed transportation to such a program.

Planning possibilities

- A component could be created for Barry in the county's nursery school by fall of 1975.
- A situation could be worked out for Barry in nursery school which would take care of the tuition since state funds could not be used but local funds could.
- A type A center (a special education classroom for educable, physically handicapped children) elementary school placement for Barry could be made, with additional involvement in regular kindergarten. Although Barry was eligible by age for the type A elementary programs, the local school principal felt this would not be the best program for him because there was not enough individual help available. He also said that the youngest child in the existing type A program was seven years old, and that there were already 25 children in two rooms. Barry's parents objected to this program, too, because there was, in their opinion, too much babysitting and not enough competition. Consequently, other possibilities were to be investigated, and the committee decided to meet again in two weeks.

After the second EPPC meeting, the local school principal forwarded a letter to the district special education staff presenting a list of special education programs he had investigated. He reported that three school districts refused to accept tuition students; one school district program was only at the discussion stage; one school district had a half-day program with emphasis on learning disabilities and emotionally impaired; and one district had a private mainstreamed half-day program.

The third EPPC, held in August 1974 at the local school district offices, resulted in the Marshalls asking to observe the private mainstreamed preschool classroom suggested on the principal's list of possible programs. Also at this meeting, suggestions were made as to where Barry would receive speech therapy services. The Marshalls eventually chose to enroll Barry in the private preschool program in the fall of 1974 and have him receive speech therapy from a local university's speech and hearing clinic.

A fourth EPPC was conducted for Barry in November 1974 at the private school located in the neighboring school district. A discussion of Barry's handicaps resulted in what now appears to be a pattern in this case. The county special education director suggested that Barry be defined as educable mentally impaired. The local school district psychologist stated that perhaps Barry should be described as learning disabled. His teacher from the private mainstreamed preschool classroom stated that she saw him as more speech/language and physically impaired, and agreed with the school psychologist that learning disabled was a possible diagnosis in this case. The special education director mentioned that Barry had been considered for placement in the local school district's Orthopedic Room. Mrs. Marshall made it clear that she did not regard the Orthopedic Room as an appropriate placement for her son, nor did any of the other professionals who had contact with Barry.

Conflict arose when the special education director reported that he would not recommend to the intermediate district superintendent that the district reimburse the costs of Barry's transportation to the private mainstreamed preschool. The local school district principal stated that, under those circumstances, he would have to recommend alternate programming for Barry. Mr. and Mrs. Marshall were very displeased at this turn of events. An argument then ensued about the possibility of setting up a program in the local school district for Barry and several children like him, and the adequacy of such a program. Mrs. Marshall made the point that she would like to observe such a program and be certain of its existence before agreeing to place Barry in it.

Discussion continued as to possible alternatives to the transportation dilemma. The director of special education noted that the Marshalls had the right to appeal the decision for no reimbursement and a change in placement. (The Marshalls, in fact, did appeal, after two more EPPC meetings.)

The refusal to pay for Barry's transportation to a private program apparently had a basis in then-existing state policy. (A month later, the Marshalls received a letter from the school principal notifying them that the state department of education would not approve reimbursement of transportation for Barry to the private school by the local district.)

Alternative programming for Barry proposed at the November 1974 meeting included: 1) that Barry be served through the local public schools as soon as possible, regardless of the reimbursement issue; 2) that Barry be served through the private school until the end of the year, if the state would reimburse at least 75% of his transportation costs (as mentioned above, the state later refused to reimburse any of his costs); and 3) that Barry be served indefinitely by the private school.

The issue of Barry's handicap was again raised. It was agreed that he should be evaluated, for the first time, by a diagnostic team from his intermediate school district, prior to a December (1974) EPPC meeting.

The psychological evaluation was conducted on December 6, 1974 (Barry was five years and five months old). Statements from the report follow:

- "Without aid, Barry did not correct his errors, needs much structuring of tasks."
- "Receptive language skills are much more advanced than expressive skills."
- "Based on his performance on a non-verbal intelligence test, Barry is functioning like a mentally impaired child. However, it should be noted that Barry displays an uneveness of profile that is atypical of these children. For this reason, psychological re-evaluation should be done at least yearly."

Recommendations from the report included: 1) extensive speech therapy; 2) emphasis on language development; 3) scheduled periods of gross motor activity (not to be confused with recess); 4) primarily non-desk activities--Barry is more at the free play stage; 5) when working on academic tasks, Barry will need much individual attention from an adult who can structure and organize the task for him.

The fifth EPPC was then held on December 11, 1974. The local principal outlined his plans to develop an appropriate program at the local school for Barry. The university speech clinic director testified that Barry needed an intensive speech program and that with a behavior control program, he could sit and do work. The local school speech therapist stated she could not give 1½ hours of speech daily to Barry. The county special education director stated one hour a day would be possible, by "bumping" existing lower priority children from case loads of other speech therapists.

Once again, the Orthopedic Room at the local school was suggested as an alternative placement since there still was no agreement in Barry's diagnoses. Mr. Marshall said they would probably appeal such a decision. At this point, the EPPC voting members were polled regarding Barry's handicap. The proposal voted on was that Barry was diagnosed as EMI (educable mentally impaired), LD (learning disabled), and POHI (physically or otherwise health impaired). All voting members approved this multiple diagnosis. Those who did not vote included: the university speech clinic director, the university speech pathologist, two local speech therapists, the teacher from the type A classroom, an occupational therapist and the Marshall's parent advocate. Those who did vote included the local school principal, the school psychologist, the parents, the special education director for the county, and the private school teacher.

The special education director then recommended that Barry be changed to the local school's Orthopedic Room on the following Monday. The voting members reached a tie vote on this recommendation, so another EPPC meeting was set. The three dissenting votes were cast by both parents and the private school teacher. The school principal stated that he would take under consideration adding a speech therapist to the list of voting members, at the suggestion of the private school teacher. Here it is clear that the Marshalls were able to bring about the continuation of discussion (in the form of yet another EPPC meeting) and to affect the form of decision-making (adding a speech therapist as voting member) through their active participation in the EPPC meeting and their votes; there is no question but that they had at this point an equal voice in decision-making for Barry's education.

The sixth EPPC meeting was held in January 1975. The local school principal stated that the school's afternoon EMI (educable mentally impaired) program was then in operation. The other half-day alternatives would be the Orthopedic Room (under a POHI classification), or EMI placement with older children, which the principal did not feel would be appropriate for Barry. The question of the amount and type of speech therapy Barry would require was then discussed. The special education director protested that he could not subscribe to Barry's receiving one daily hour of individual speech therapy because he did not have the staff to provide this service to everyone, and that Barry should receive the same treatment as other children in the district with parallel disabilities. These protests were ignored in the group's recommendations.

Prior to approving recommendations, the parent advocate pointed out some reasons for the Marshalls' frustration with the continuing series of EPPC meetings. She stated that the Marshalls were basically satisfied with Barry's current placement in the private school and did not want to change it; instead they were asking for transportation reimbursement. The advocate also stated that when alternatives were introduced at these meetings, the parents were not being provided with any specific curricular or program descriptions about them.

The committee then produced the following recommendations:

- Barry should receive one hour of individual speech therapy daily, plus one hour of group language;
- Barry would be assigned to the POHI room for a half-day, and to the EMI room for a half-day;
- A written evaluation of the total program would be produced by two months after the present date;
- The program would start within two weeks;
- Barry's program would include integration with normal children in supplementary activities such as music, gym and art, and that it would encourage Barry to become more independent.

It should be noted that the school district felt it had done a considerable amount of accommodation to the Marshalls in reaching these recommendations, both in the double placement and the extraordinary amount of speech therapy scheduled. The amount of mainstreaming was undoubtedly viewed by the school district staff, also, as appropriate; but it was not specified in detail to the parents during the meeting. The Marshalls were initially fairly satisfied with the results of this sixth EPPC meeting, but after receiving the meeting minutes and detailed written recommendations, they rejected the recommendations and asked for the first of three hearings. Mr. Marshall testified at that hearing, held in late March 1975 at the local school district offices:

> "It all goes back to the original goal for Barry, getting a place with normal children--with normal speech stimulus. We are not meeting the original recommendation. He is an orthopedic, learning-disabled child now. He is approaching normality and is being put down again. With an aide and teacher, we were told it was impossible to put him into a classroom of 30."

After much discussion, involving the Marshalls' lawyer, the hearing was adjourned. Another hearing was scheduled in April, and once again in May, again at the local school district offices. Findings were forwarded to the state department of education, and a decision rendered in favor of the local public school system. The hearing officer did recommend that Barry should receive a POHI evaluation by a physician specializing in this area.

Upon studying the decision, the Marshalls' lawyer advised them to pursue further actions at their local school level. These have brought Barry to his current setting (at ten years of age)--in a self-contained EMI classroom, and mainstreamed in music, gym and art.

Details of the Marshalls' interactions with institutions, agencies and officials over the years since 1975 are discussed in the following section, dealing with the impact of specific provisions of the law.

II. The Five Major Provisions of the Law As They Relate to the Marshall Case

Protection in Evaluation Procedures

The Marshalls have used evaluations repeatedly and effectively in pursuing appropriate placements for Barry. They are aware of their rights under this provision of P.L. 94-142 and have exercised these rights on Barry's behalf. This provision has worked effectively for this family as far as the letter of the law is concerned. The Marshalls have very positive feelings about the number and quality of evaluations conducted on Barry, but they have not been satisfied with the placements which have resulted from these evaluations. Their sense of the "rightness" of their son's evaluations is very strong. To quote Judy Marshall: "I feel we have enough reports by experts, enough data that say Barry must be given more than he is getting--it's not just me, his mother, demanding."

Each year the Marshalls do face more evaluations despite their sense that Barry has become more and more "test wise" and more adept at manipulating testers. Judy Marshall states, "I continually tell them that he will manipulate a male and he should know most of those tests by heart but they still use males and again this spring (May 1980) he was evaluated again." Barry's spring was a busy one as the summer speech camp director requested another evaluation (administered in March, 1980) because Judy Marshall wanted signing to be part of Barry's speech program during the six week summer camp. It does appear that there could be more acceptance on the part of professionals of test results and less pressure on the child and parents to repeat a process over and over.

In sum, the law has provided the Marshalls with the mechanism and protection to accomplish a major task--they do have a sufficient number of well-conducted evaluations of their son. Barry has been evaluated in over 40 different situations, by professionals in six to eight different institutional settings. And the Marshalls will continue to do what they have been doing--use the evaluations in their battle to obtain an appropriate placement for their son.

Procedural Safeguards

Although the letter of the procedural safeguards provision has been followed, placement rulings have pointed up differing interpretations of the law by Barry's parents and local school district officials. The Marshalls have used the legal procedural safeguards to the fullest extent possible. There has not been a breach of the parents' rights or lack of proper prior notification in relation to either the EPPC's or meetings regarding the Individualized Educational Program (IEP) for Barry. The Marshalls have attended all of the placement and program change meetings to which they have been invited by notification letters. They have exercised their rights to refust consent prior to placement on two occasions. This provision has also provided the Marshalls with the opportunity, nine times, to disagree with the decisions made for program placement for their son.

The Marshalls feel that this provision gives parents a strong voice in the process of placing a handicapped child. They have seen all diagnoses and relevant reports prior to placement meetings and they know who is making what recommendations, the information upon which those recommendations are based, and, finally, they know they have the right to accept or refuse placement.

While it is quite apparent that this provision gives the parents the right to due process hearings if they disagree with a recommendation for placement, the Marshalls feel that, in their case, their efforts have become exercises in futility because the placement rulings have all been in favor of the schools. In 1974, under the State Special Education law Barry was placed in a mainstreamed program in a private school outside the local school district. After observing gains in Barry's development while he was enrolled in that program (e.g., better concentration, ability to plan and execute an activity, improvement in social skills), the Marshalls believed they had found a program that met Barry's needs. But since this particular mainstreamed program was in a private school outside the Marshall's local school district, the local district ruled not to provide transportation to the private school. School officials believed they were able to provide an appropriate educational program for Barry locally. The controversy over Barry's placement appears to be centered around the definition of "appropriate". The law states that each handicapped child is entitled to "a free appropriate public education." The Marshalls feel the "public education program" offered is not appropriate; the school officials feel their program is appropriate. P.L. 94-142 has not made any more, or less, impact on these decisions.

The ruling officer, in attempting to resolve this difference of opinion, has determined that the letter of the law has been met; there has been no breach of constitutional rights; the EPPC's have been conducted properly; and the school has attempted to provide an adequate program to meet Barry's needs. At this time, then, the Marshalls have accepted the ruling and are trying to work constructively with the district (see next sections).

Individualized Education Program (IEP)

Since Barry's placement in 1977 in the local school district program, his mother has received proper notification of the IEP's and she has attended these meetings at the school with the teachers and speech therapist. Because of the major role the EPPC's play in a child's placement in Michigan, Mrs. Marshall at first did not comprehend the value of the yearly IEP process at the local school level. She soon found, however, that the IEP meetings provided an opportunity for her to monitor the curriculum being used for Barry. Her attitude now toward the IEP's is quite clear: "I didn't put much stock in them (the IEP's) at all and didn't really think that much about them. All of a sudden, I find out it's a review, like an EEPC, except that it's not an educational change...and I did get signing put in the last IEP."

At this time (June 1980) Barry has spent a full school year working on goals set out in the 1979 IEP. Judy Marshall attended Barry's latest IEP in April (1980). She said that she felt the IEP looked good on paper but felt it did not always go as planned or requested. "You assume it's going on, but you discover someday along the line that some things have slacked off or stopped." Judy had pushed for signing--a positive way for Barry to communicate with others--and saw a plan set up to allow for this. Judy was traveling to another city to an elementary school (at her own expense) taking signing classes to be part of the plan to provide Barry with a means to communicate with less frustration. However, over the school year the well-planned collaborative program seemed to disintegrate. While the speech teacher set up a program of signing and speech three times a week and started to work with the EMI classroom teacher, this program lost momentum during the year. Judy feels this happened because Barry is not hearing impaired; therefore, no one really feels the need to work on signing. "They act as if it's some whim of mine. It seems like they (educators) would want to do anything that would let Barry get his ideas and needs across, let him work and learn at his highest potential. I know I'm the person who has to push for this (signing) but I don't know the right words to use. I never could come up with the right language. If they would take out the 'mother image' and give me some credit for intelligence I'd feel better."

There also appears to be an issue of IEPs piling up and a feeling on Judy's part that they are carried out in assembly line fashion. "They take two days and just push IEPs. There are so many forms and paper work--I feel I can't get much accomplished. It's like Barry is just being pumped through the system. I can't help but wonder how much of the IEP is done because it's law and how much is done out of genuine interest in Barry reaching his potential?"

While Judy Marshall appreciates the opportunity to be a part of the planning for Barry's individualized education program, she has identified some potential weak "links" in that process. How does a parent monitor what is actually happening versus what was planned on paper? Are professionals overwhelmed by the rules, regulations and reams of paper needed to uphold the law? If that is the case then it is done at the expense of carrying out the law in <u>providing</u> the "individual educational program" to the child! Judy Marshall's question stands--"Which is the most important to my child?"

Least Restrictive Environment

The Marshalls have paid a high price in terms of physical and emotional energy to guarantee their son the least restrictive environment placement. Barry has been processed into and out of three educational settings since 1972. The Marshalls have gone through nine EPPC's and two hearings to get him to his current setting, which is still a compromise--a second choice--as far as they are concerned. The schools, however, feel they have met the intent of the law by providing a program for handicapped children, including Barry. They have housed this program in one school and it covers LD, EMI, EI, POHI, TMI and SMI. The Marshalls had the option of either accepting the local program or paying for Barry's education and transportation themselves if they decided to leave him in the private school and mainstreamed setting he was in at the time of the hearing.

The Marshalls have, in a sense, invested the largest part of a considerable effort in getting Barry placed in what they believe is the least restrictive environment in which he can function appropriately--a mainstreamed setting. They feel that this large investment of energy and resources has produced the least gain, in that they have been completely unable to get the mainstreamed setting they want. While they are clearly satisfied with the changes obtained through their efforts, and with the amount of control they have had, they feel these small gains will always be overshadowed by the fact that they lost the "larger battle" of overall placement. Although the EPPC recommendations included in the options placement in the private school in which Barry was enrolled at the time of his hearings, they did not provide for reimbursement from the local school system. As Mrs. Marshall stated, "the private school program was no longer an option for us under those circumstances."

The Least Restrictive Environment Provision appears to bring about the greatest disagreement between the public schools (and their strict interpretation of the intent of the law) and the Marshall's quest for the most productive Least Restrictive Environment placement for Barry. The due process right to refuse consent has been painful and at times costly for the Marshalls. They tried to absorb the costs of sending Barry to the private school for a short time but found it prohibitive.

The Marshalls have used all five provisions of the law, but lean heavily upon the Least Restrictive Environment Provision. They have used it appropriately and, on occasion, effectively for Barry's placement. But the law cannot protect them during their meetings with the professional EPPC committee members. It is during these highly charged, too often polarized meetings, that parents such as the Marshalls feel threatened and inadequate in trying to do the best for their child. Mrs. Marshall has shared these private feelings with us: "Where I have been put down the most is at the EPPC's. You're the parent--and that's the limit. And I feel threatened at that point. If they would talk to me like I had a little bit of intelligence...I brought him into the world, I've got the problem, and I'm living with it...I'm going to have him all of his life. So--give me some credit--you know?--that I have some sense of where we should go with him."

Parental Involvement

In 1971, Judy Marshall returned with Barry to the hospital where, in 1970, he was admitted on suspicion of meningitis. She thus took the initiative in getting him started on the series of tests and evaluations that had only been suggested to her the previous year. That was the beginning of the Marshall's long-term involvement in seeking appropriate medical and educational services for Barry. They have made it a point to stay involved. They visit various educational programs that have been offered as optional placements for Barry. They observe in the classroom and talk with the teachers and therapists in order to understand just what the program will offer Barry and determine if they feel it will meet his needs. They have sought out and taken into consideration professional direction and advice relevant to Barry's educational welfare. They have responded to all notifications of meetings and hearings. They have maintained this vigilant involvement while feeling at times extremely frustrated and "put down" by a professional cadre that has continued to grow each year, at each meeting, at each evaluation, and at each program placement.

In 1976 the Marshalls discovered that their satisfaction in finding an appropriate placement for Barry in a mainstreamed classroom in a private school was to be short-lived. The local school system would not continue to provide transportation to this program. When it became apparent to the Marshalls that they might have to give up this program, they turned to the provisions of the law, using the process appropriately--but lost. The Marshalls say that they have no complaint with the process itself. Their parental rights are protected throughout the process. The larger question they pose is, "Is it worth all that it takes to go through the due process hearings and lose so often?" Again, the Marshalls want the positive aspects of their story told, as well as the negatives. They feel the process is worth the effort. As a result of the last few EPPC's, there is now a real special education program in their local school. The school district has made an effort to hire appropriate teachers and therapists. The Marshalls feel that it was their fight for Barry's right to a free and appropriate education that was instrumental in pushing the school into developing a program that is benefiting other families with handicapped children in their rural area.

Mrs. Marshall states: "In a multiple handicapped child where do they gear their decisions? Services to the greatest handicap--or the least? Why has no one at the schools or EPPC meetings recommended a Learning Disabled program for Barry? All of his evaluations stress his abilities being limited by speech, not physical handicaps. Has anyone asked us to observe with them (the professionals) and talk it over? Who cares? Do we (parents) say, 'Well, he's in a program, don't rock the boat, I've had it, no more arguments, no more problems?' Me, as a person, I say it's like going to a job, do a good job and you get a chance for advancement. It should be like that for Barry. A chance to do better. I keep asking these questions, and are we doing our best? We, the parents, and 'we', the schools?"

At the end of the 1979-80 school year Judy Marshall is expressing some real concerns for Barry's future (which also includes her future): "Time is slipping away from me. Next year is his last year at the elementary school. Have we done our best for him? I just don't know."

The Marshalls continue to stay involved in Barry's educational process at times at their own expense. While they have appeared at all the meetings, hearings, evaluations, etc. that professionals have summoned them to, they feel that their input is rarely taken seriously. They had hoped to advocate, use the law and bring about a better education for Barry by being "involved." They are beginning to show signs of "burn-out."

III. Major Issues of the Marshall Case

In the preceding sections of this document, the relevant impacts of the law and related issues were documented for each of the five major provisions of P.L. 94-142. This section presents another way of looking at notable features of the Marshall case, features that cut across the major provisions and highlight areas in which adherence to the spirit or intent of the law does not necessarily equal adherence to its letter. These areas also represent aspects of the present case that the researchers will continue to follow up and explore in greater depth in the future.

Ongoing Placement

Judy and Ronald Marshall have invested themselves heavily in their quest to provide the best educational environment possible for Barry. This has been a financial as well as emotional hardship on this couple. Mr. and Mrs. Marshall want Barry to have more challenge and opportunities to be with normal children in a normal learning environment. It appears that placement in a program providing the least restrictive environment will continue to be an issue with this family as Barry continues to move through the school system over the next several years. Mrs. Marshall's analysis of her dissatisfaction with Barry's current placement is as follows:

> "I don't particularly agree with mainstreaming at this point. Idealistically--in my heart--that's the way I'd like it to be. But I don't think it's doing the job that they expected--what their idealistic ideas for it were. It's not working for Barry. Now he's getting mainstreamed. What they call mainstreamed is music, art and gym. And I say, whoopee. I would rather they keep him within the (self-contained) classroom. Gym? Fine. Now that's something he can do with other kids if the teacher is willing to work with him. Music and art? I feel they are the losers... Barry is the loser. The teacher does not have time to spend with 30-some students and Barry.
>
> I don't know about the other counties around here, but ours has every special education class within one building. I feel one building's teachers shouldn't be burdened with all the mainstreamed kids. Here they've got LD, EI, POHI, TMI, SMI and EMI. You can't expect them (the teachers) to take all that. They (the children) should be placed in different schools. I don't think in public schools you have the freedom to make those kind of suggestions, you know, as a parent."

Judy Marshall continues to feel strongly about Barry's placement. At the end of the 1979-80 school year, Barry was evaluated once again. Judy talked with this evaluator about her concerns over Barry being removed from his EMI classroom so often in the name of mainstreaming. Her statements and questions were valid ones. We would like to share them:

> "At Barry's elementary school, the 'normal' kids get to school, go to their classroom and stay together. They go out to recess and lunch and out to gym class. All the rest of their learning is done together. Now the kids in Barry's EMI classroom are expected to go out of their classroom for speech, art, music, gym, and some go for math and reading. These are handicapped kids who are expected to learn in this kind of in and out, all day, everyday environment. They (handicapped EMI) need the same, if not more, continuity in their lives as the normal kids. It's not fair to them to continually take them in and out of their classroom. And all in the name of mainstreaming! The normal and handicapped play together at recess and gym and socialize at lunch. The handicapped kids go one or two at a time into these normal art and music classrooms. It's like segregation, not mainstreaming. They are never a real part of that classroom--just an 'outsider' who drops in once a week or less often in some cases. We are asking more of the handicapped child than we are the normal ones. Who are we mainstreaming then?"

Facing the Realities of the Child's Handicaps in Relation to His Future

Barry is now 11 years old and rapidly outgrowing the "cute little kid" stage. Judy and Ronald Marshall are starting to take a look at the lifelong commitment a child with Barry's limitations necessitates. They believe they have accepted the fact that he is handicapped and feel they understand his handicaps as much as possible given his uncertain diagnosis. They are working diligently toward improving his means of communicating with his world. They feel many things he does point to the fact that his inability to communicate hampers his progress. No one can really tell them where he will go developmentally because of his severe speech impairment. One tester related that Barry was having a problem drawing two overlapping circles. He pondered his plight a few minutes, then removed his glasses and traced around them to create the two overlapping circles. It is at moments like this that parents such as the Marshalls feel a tiny hope spring up again, that makes the battle to provide every possible opportunity for him to learn worth it all.

The Marshalls take advantage of every opportunity to provide Barry with contact in the world outside home and school, including short stays away from home. In 1979, Barry attended a summer speech camp for two weeks. His mother laughingly points him out in the group picture he brought home with him. "Look, there he is with his tongue stuck out. I

guess that was his general opinion of going away to camp for two weeks." She also shared some insights with us concerning their attitude toward Barry's future, regardless of how uncertain it looks now at 11 years of age. Her remarks are very candid:

> "We are already talking about going to speech camp next year (1980), and he's already saying, 'no way.' I tell him 'you don't have a choice, Barry. Guess what, if it's good for your speech, you're going.' Oh, I think he feels good about it, it's just that he's very close to us and we tend to be very close to him. I think being away is not his number one goal in life but I've got news for him. He's got to get used to it, because he is going to be doing a lot more of it in the future. If it's at all possible for him, I'm not going to babysit him for the remainder of his life. He's going to have to do something, go somewhere, and function somehow in this world. As much as I would like to protect him, we've done more than our share of that. He's getting to be a big kid now."

Some major changes have taken place in the Marshalls' lives since Judy's above quote in the fall of 1979. Barry's older brother expressed interest in going to a Christian Academy in a southern state. A cousin was attending and therefore he was familiar with the school. The Marshalls visited the academy, talked it over seriously as a family and decided to let Jerry try it the 1980-81 school year. It was not an easy decision for the Marshalls to come to. It will mean both a financial and emotional strain. The family is very close-knit and they sense that they are going to miss each other a great deal in the beginning. Judy stated: "Although Jerry has never come right out and said anything, I'm certain part of him wants to get away from Barry. Barry takes a lot of our attention and energy I know. He also demands more of Jerry too, now that he's getting bigger himself. I think Jerry needs this chance to get away and we'll give it to him. It sure won't be easy and we've told him. 'We are still the parents here and we will continue to make decisions, but if you don't like it say so, and you can come home.'" The Marshalls received official notice in June that Jerry has been accepted and is expected at the school on September 2, 1980. Judy said Jerry had the card on his bulletin board with the date underlined.

Another interesting turn of events that is significant to the case study is a decision on the part of the Marshalls to move to another county. Over a year ago a friend of Judy's invited her to go visit some group homes for the handicapped in an adjoining county. Judy was quite impressed with the physical appearance of the homes and the manner in which they were governed. She inquired about putting Barry's name on a waiting list even though he was only ten at the time. She was informed there was a seven-year waiting list; therefore, it would be appropriate to get an application in early for a child. While pursuing that notion, Judy discovered they also had job openings for caretakers to cover weekends.

She inquired into that possibility for herself and was eventually hired. She does the cooking and manages the house and clients over a weekend period covering Friday evening to Sunday evening. Before taking this job another major family discussion/decision session was held as it meant Judy would be away from home and Ron and the boys would be on their own. Since Jerry's school tuition was going to be an additional expense, everyone agreed to try out this arrangement and to date it has worked out well for the family.

Probably the most significant decision this family has made recently in relation to their handicapped child is the one to move into one of the residential group homes as "house parents." A new one is being built this year with a large apartment (two bedroom) to house a family. Judy would then do the managing, cooking and supervising the clients on a full-time basis. Of course, Barry would then live with them in the apartment but be able to socialize with the other handicapped clients. The depth of the Marshalls' concerns for the entire family surfaces in Judy's remarks concerning this decision:

> "We decided not to risk everything on this move. We will not give up our home out here in the country. My parents have agreed to come and live in it. I've taken both boys with me on several occasions to the group home I work in to let them get the feel of it. Ron can still do his job from that county as it's right on the border line. Also, Jerry will be going off to the academy so he will not be there full-time. We are going to try it and if it works--great--if it doesn't then we can come back to our own home. It has to work out for all of us."

LARRY CORWIN

I. Introduction

Brief Case Sketch

Larry Corwin was born in July 1970. His development appeared normal to his parents during the first two years of his life. His birth history was also reported to be normal. When Larry was two, his parents noted that he did not seem to understand commands, nor was he able to indicate his wants. When he was four his parents, increasingly concerned about his language development, brought him to the speech clinic at a nearby university hospital. Apart from delay in language development, it was discovered that Larry had a profound hearing loss in his right ear, and a mild loss in his left ear. Larry also had a history of multiple ear infections during his early years.

During the next few years, as Larry's contact with educational institutions increased significantly, and periodic evaluations were done, a complex diagnostic situation developed. Larry's hearing loss was unquestionable, but he was able to understand speech that was clear, reasonably close, and not confounded by surrounding noise. When he was five, teachers and evaluators observed Larry to be functioning socially and intellectually at a three to four year old level. His strengths were in his affectionate and friendly interactions with others; his desire and willingness to take on special tasks; and in his ability to learn when problems were presented in a visual mode. His problems were primarily in his high distractibility, hyperactive behavior, short attention span, inability to respond to directions, and need to control social interactions with peers. Anxiety and fear were also noted in his behavior at times. One teacher noted that he was "very considerate of other children who had been hurt or who seemed sad."

This pattern of behavior has continued, with slight modifications, to the present. Larry is now close to ten years old, and his intellectual and social progress has been described by teachers and evaluators as limited; he is seen to be functioning at about the level of a five year old. It appears that the demands of schooling have been generally overwhelming for Larry. His cognitive skills have improved only moderately since he was four or five years old. Socially, he seems isolated, somewhat fearful, and extremely easy to upset.

None of the records of evaluations and observations, or the professionals who have had contact with Larry over the years, seem to be able to identify the causes of Larry's problems. There is a feeling that his hearing impairment has something to do with it; that emotionally Larry is an extremely "needy" child; that perhaps there is some minimal brain damage. But whether the effects of a hearing problem have been magnified by emotional problems;

whether intellectual retardation is due to emotional impairment or some organic condition, are simply not clear. Larry's parents and teachers have noted that his hearing is selective--he hears and understands when he wants to. But he all too often uses his hearing loss to "tune out" reality. Many of the social and intellectual demands of daily living appear painful to him.

Larry's educational history reflects the lack of consensus about the causes of his problems. Upon recognition of his hearing loss and its effects on his language development, Larry's parents started him in speech therapy at the university hospital clinic and nursery school at a private nursery school in August 1974. This arrangement was continued until December 1975, when a decision was made in Larry's first EPPC that Larry had made enough progress in his development to place him in a regular public school kindergarten on a trial basis for six weeks. He was then five and a half years old. His behavior in the public school kindergarten was seen as inappropriate to that setting, and a second EPPC meeting in March 1976 led to a new placement in an integrated preschool program for handicapped and normal children at a local private educational research agency, with speech therapy at a second university in the area. An evaluation at that time included the following comments:

> "When interactions involved more than casual social contacts, his basic slowness, immaturity, and anxiety was evident. He became extremely impulsive, with many scattered responses and little evidence of good internal controls... He might learn to deal with day-to-day problems more effectively if he were required only to meet demands within the range of his abilities... Placement among children his own age who are functioning at a higher (average) level will probably not set an example to be imitated but raise his anxiety level and increase unfocused behavior."

From March 1976 to June 1977 Larry remained in that preschool program, receiving regular speech therapy. Progress was noted by staff from both programs. In June 1977, at the next EPPC meeting, a decision was made that Larry was ready for public school. He was placed in a regular first grade classroom in a school in a neighboring district having an Educable Mentally Impaired (EMI) program that he would participate in part-time. This arrangement lasted for one year. In September 1978 he was placed in another elementary school in his own district, with a teacher-consultant and aide to work with him. This lasted only till February. At this point he returned to the first elementary school, and finished the school year. During the 1979-80 school year he remained in this school, with a dual placement in the EMI and EI (Emotionally Impaired) programs of that school. Speech therapy continues in the school setting.

As will be described shortly, Larry's placement history reflects a good deal of negotiation among parents, evaluators, local educational agencies, and teachers. It also has been characterized by trial of a variety of service alternatives. At present, he is in third grade, and receiving special services under a double classification as both emotionally impaired and educable mentally impaired. Larry takes regular medication for hyperactivity.

The Corwins live in a small town in a semi-rural area of Michigan. The nearest urban area is some twenty miles away. Larry's parents, Jeanne and Richard Corwin, work in manufacturing plants in the auto industry. Both have worked a number of different shifts over the years, and the possibility of lay-offs is a perennial feature of their lives. (Jeanne is currently laid-off, but receiving sub-pay, which after baby-sitting costs saved, is equal to her working pay.) In spite of job insecurities, the family appears to be in reasonable financial shape.

The Corwins have six children: a baby boy born in 1977, and five others ranging in age from sixteen to nine and a half (Larry). The second oldest, Robert, is in eighth grade, and in the last two years his parents have become extremely concerned about his reading problems at school. About a year ago they started an evaluation process for him that has finally led, after considerable conflict and negotiation, to his receiving special services within the middle school setting. They feel Samuel, the youngest, is an "exceptional" child, very bright, perceptive, and verbal. In fact, they are concerned that he is catching up to Larry. Jeanne Corwin has expressed it this way:

> "Samuel is beginning to catch up with Larry, and I'm afraid. I don't want to hold Samuel back, and I'm not going to, it's not fair to him. I feel, though, that maybe Larry will start noticing...I don't want him to turn around in two years and say boy am I dumb, here's my five year old brother; why don't I know that, he's five years old and he knows that."

The Corwins' main concern with respect to Larry recently has been his tendency to retreat to a fantasy play world much of the time, both at home and in school. This world is populated with television and other imaginary characters, and Larry can easily spend long periods of time in it, talking to these imaginary playmates. A staff member of a local community mental health center, with whom the Corwins have some contact (this contact requires further looking into) has told the Corwins that Larry needs this, and that eventually he will outgrow it. But they are concerned that it interferes with Larry's learning, especially in school.

The Corwins are increasingly looking to the future, and wondering how competent Larry will be to take care of himself. Their concern for his fantasy play interfering with his learning is an expression of this consciousness of the future. Jeanne Corwin has noted:

"He seems to be doing all right, but I'm beginning to feel anxious...I know he has till he's twenty-six, that he can go to school and continue his education, but he'll be ten in July and ten year old children at least know their alphabet."

Both parents project a sense of care and loving concern for their children in general and Larry in particular. Because there are six children in the household, things can get quite hectic. But they try their best not to lose him in the shuffle. Having Larry's needs met has clearly been a central and continuing concern to the Corwins; they appear to be increasingly aware that this will require a good deal of time and energy for many years to come. They mentioned that a mental health official told them that while Larry would never be an aeronautical engineer, he'd learn to support himself in due time. That, they said, was the most hopeful thing anyone had said to them in some time.

A Chronology of Contacts with Institutions and Service Programs[1]

As has been mentioned earlier, Larry's early development gave his parents no special cause for concern until he was approximately two years old. At about age two, Jeanne began to worry that his speech was not continuing to develop and that he did not seem to respond to spoken commands. Medically, he had a history of repeated multiple ear infections. In March of 1974 he had his tonsils and adenoids removed, and underwent bilateral myringotomies. Referred at this time to speech clinic in the pediatric section of a large university hospital in a nearby urban area, he was examined there in July 1974 (at age four); the examination found a profound loss of hearing in his right ear and a mild loss in his left. Recommendations included further examination and the provision of speech therapy. Psychological examination at this time showed some overall delays.

The Corwins placed Larry in a private mainstreamed preschool in the urban area, and provided speech therapy for him through the university speech clinic. These placements lasted through November 1975 (until Larry was five years, four months old). His teachers initially noted difficulties understanding his verbalization, as well as in coping with his high activity level and short attention span: "he seemed to flee the room within seconds," one report stated. Over this period progress was noted in his language, and in his capacity to attend to tasks and to take responsibility for his actions; he also showed considerable growth in cognitive aspects. Through this period, the Corwins paid for the preschool and provided their own transportation for Larry.

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[1]This section remains the same as reported in the first year annual report up to the end of the 1976-77 school year. It has been substantially modified from that point on, and presents an account of the implications of a school district's failure to comply with state and federal special education law, with a resulting state investigation.

Psychological re-examination at the university hospital in May of 1975 (age: four years, ten months) reflected his teachers' sense of progress in Larry. His examiner found fourteen months' growth in Larry's mental age over a ten-month period, and said: "I still leave it open (as) to his actual intellectual potential." The Corwins at this time were planning to have Larry enter kindergarten in the fall and possibly stay there two years; the examiner found this plan most appropriate for Larry's stage of development. A re-evaluation of Larry's speech status by the university clinic also reported considerable progress in October 1975.

Against this background, Larry's first EPPC meeting was held by the school district in December 1975. Jeanne Corwin attended. The committee recommended entry in January 1976 for Larry into the local school's kindergarten on a trial basis for six weeks.

Problems with distractibility and hyperactivity, as well as disruptive behavior and lack of retention of materials and skills previously encountered in the nursery school, surfaced quickly in the kindergarten setting. By early February 1976, the school district was conducting further evaluations of Larry, and requested that the intermediate educational agency send an examiner from its center for trainable mentally impaired children to further evaluate the child. The evaluations led to Larry's next EPPC meeting, which took place in March of 1976. Again, Jeanne Corwin was present. Evaluations indicated that Larry was functioning in the EMI range, and the committee recommended an immediate change of placement, to a program that could "be highly individualized and offer intensive concepts work." It was recommended that Larry be placed in two sequential programs in yet another urban area some twenty-five miles from the Corwin's home town: a morning preschool program at a private educational research organization that provided a mainstreamed setting; and an afternoon intensive speech therapy program at a speech and hearing clinic in a college in that urban area. These programs were offered at no cost to the parents, and the district undertook to provide transportation for Larry to the programs.

Enrollment in the new placements began in April, and a third EPPC meeting was convened in June 1976 (by then Larry was almost six years old) to review their results. Mrs. Corwin was once again present; the school district was represented by the director of special education, and both service agencies sent representatives. It was agreed that current settings were appropriate, and summer speech therapy and placement in both settings again was agreed upon for the school year 1976-77.

Both programs provided reviews of Larry's development during the following year. The college's speech and language clinic gave Jeanne and Richard guides for a home speech program; the preschool staff made home visits. Again, progress was considerable; although the clinic setting reported continued limit-testing and manipulative behavior, there were on the other hand signs of a lengthened attention span, increasing clarity in

expressive language, and much evidence of cooperative behavior with regard to other children. In particular, behavior-modification techniques seemed to be effective at least part of the time in helping Larry control his activity level and impulsivity.

The next meeting of Larry's EPPC was scheduled for June 1977. Again, it appeared to all concerned that entry into a regular school setting was a possible alternative (Larry would be seven by the fall of that year). Recalling the problems with the last attempted entry into public school, the local special education staff invited to the meeting persons from a child psychiatry clinic in the area that offered day programs, and from an area private school for EI children, as well as staff from the college speech program, the private preschool, and the local elementary school principal. At the meeting a number of alternatives were discussed. The consensus of the committee was to reconvene at the beginning of September to determine the most appropriate program for Larry.

Prior to the September 1977 EPPC the school psychologist from Larry's home district made considerable effort to find an appropriate program for Larry, based on the district's knowledge of his history and needs. The reason for this search was, reportedly because of Larry's home district did not have a program that they felt was appropriate for Larry, that was a self-contained EI classroom where Larry could work with just a few other children present. The psychologist looked into a number of the local special education regions' programs[1], also at the integrated preschool program where Larry had spent over a year. He was unable to find a program for Larry.

As the 1977-78 school year began, Larry was without a program, and was thus not enrolled anywhere. On September 21, a week after the school year began, an EPPC meeting was held for Larry. After considerable debate, the participants reached consensus that Larry was to be classified as emotionally impaired, and that a self-contained EI program would be optimal for him. The program, then available in his home district, was organized such that the EI teacher was seeing 13 children for two hours a day in groups of three or four. It was felt that this constant change in grouping would be extremely disturbing for Larry, and that he needed a situation where he could become socialized into a consistent grouping of peers.

A decision was made at that point to place Larry temporarily in a self-contained EMI classroom in a neighboring district, until his own district could arrange to set up an appropriate program for Larry. The Corwins were informed that it would take about a month for this program to be set up,

[1]In Michigan, a number of smaller districts join together into "special education regions," in order to be able to pool resources to offer a wide range of services. Children from one district can be placed in a more appropriate program in another, without special administrative arrangements.

and it "was because of this fact that Larry was placed in an EMI classroom instead of remaining out of school." Larry's home district at that point clearly indicated an intention to set up a program for Larry, by November 7.

This program was never implemented. Larry continued to be served in the neighboring district's EMI program during the months of October, November, and December. Another EPPC meeting was held for Larry on December 10, at which time his home district presented a new option for him: "direct service to Larry for less than one-half day daily from an EI teacher with the remainder of the day to be spent with an aide in a general education classroom. Speech would be offered 1 to 1.5 hours per week." No consensus on this was reached at this EPPC meeting.

A third EPPC meeting was held on December 20, 1977. Mrs. Corwin indicated that this new option was not acceptable, among other reasons because "the room for Emotionally Impaired at (her local) elementary school was without windows." The room was also reportedly very small (18 feet by 14 feet). Other participants at this meeting, most notable Larry's teacher in the EMI room and the principal of that school, felt that it would be inappropriate and harmful to Larry to put him in general education, even with an aide; it would be, they said, "the equivalent to setting Larry up for failure." Consensus was reached that Larry would remain in the EMI class to which he was adapting well and in which he was making progress, for the remainder of the academic year, "pending state approval."

At this point, a process began that is crucial to narrate in detail, because it led to a state investigation of Larry's home district's compliance in Larry's case with the state special education law, P.A. 198, and with P.L. 94-142. While at that time it was seen as administratively and legally appropriate for Larry to be placed in his neighboring district because it was part of the local special education region, there was some question as to the legality of his placement in an EMI classroom (which was already crowded) in spite of the fact that the teacher in that classroom was a unique, warm, "marvelous" teacher, who quickly came to commit herself to Larry's success in school. The superintendent of the district whose EMI program Larry was attending arranged with the Special Education Director to have a letter sent to the state, explaining the situation.

The State Director of Special Education responded, in a letter to the superintendent of Larry's home district in March 1978, that that district's schools "may not refuse to service a student in an appropriate program on the grounds that they do not have sufficient classroom space unless the school district has received such permission from the State Board of Education." The Special Education Director also wrote that:

"it would also seem that the school district is in violation of Section 121a.552 of the rules for Public Law 94-142 and the requirements of Section 504 of the Rehabilitation Act. These regulations require that handicapped students be placed in the least restrictive educational setting. Specifically Section 121a.552 indicates that each handicapped student must be placed in an appropriate program and, unless a handicapped child's individual educational program requires some other arrangements, the child is educated in the school which he or she would attend if not handicapped.

Given the information at hand, it would seem that this student could attend a regular education program in his home school district provided the school district hired necessary personnel. We understand that his district's school has no available classrooms. The school district has the option of seeking a deviation from the State Board of Education if they cannot service students due to lack of classrooms, or obtaining portable classrooms, building on to existing buildings, or developing some other alternative to make classroom space available so that handicapped students can be appropriately serviced."

Finally, he noted that he was recommending that the Director of Special Education of the Intermediate School District (a county-size jurisdiction, acting in a service capacity to local districts in Michigan) initiate an investigation of the situation.

This investigation was carried out during March of 1978, with a set of findings submitted to the state at the end of March. The findings were tied to Michigan's state law, and Larry's home district was found to be in violation of the law in a number of areas, among them:

(1) the superintendent had not initiated appropriate special education services within 15 school days after Larry's parents had been notified of a placement decision;

(2) that Larry was never placed in an EI program, in spite of an EI classification;

(3) that the classroom space used by the teacher/consultant for EI children was inadequate, and did not meet minimal criteria.

Larry remained in his EMI classroom for the rest of the 1977-78 school year. His teacher and principal were somewhat concerned about the placement, because there were 16 children in the classroom with Larry, which made it difficult to give him the individualized support needed. Nonetheless, he was becoming part of the class, and had developed a close relationship with one of the other children in the class.

In 1978 another EPPC meeting was held for Larry. In attendance were school level staff from both districts, a school psychologist, a social worker, Jeanne Corwin, and a parent advocate. The Corwins wanted Larry back in his own district next year, if at all possible. Consensus was reached that Larry would be classified as EMI and EI. This was the first mention of a dual classification. It was decided that Larry would be placed in the second grade at his home elementary school next year, with a "program designed to keep him with his class for academic work he can handle, but relieve him from tasks that will frustrate him excessively..." The special education teacher will be available to Larry four and one-half hours per day, and have responsibility for him the entire day. He will be mainstreamed when possible.

That summer the assistant superintendent for Larry's home district wrote to the state special education compliance officer, in response to the findings of the investigation,

> "Larry will be enrolled in (his home school district's) emotionally disturbed program...he will be served in a self-contained situation... He will be housed in a room 14' x 18' which the teacher consultant for EI uses to serve small groups of EI students. The regular classroom is not available because of the extreme overcrowded conditions in (his home elementary school) for <u>all</u> students..."

Larry began the 1978-79 school year in his home elementary school. He spent the majority of each day working one-on-one with an EI teacher, an EMI teacher, a speech teacher, and an aide. He received about 20 hours a week in one-on-one instruction, and spent the rest of his time in a second grade general education classroom reportedly moving around quite a bit during the day. A review EPPC in November 1978 recommended a continuation of that placement, as it was seen to be adequately meeting Larry's needs.

The Corwins have reported an increasing dissatisfaction with Larry's placement in the above setting as the 1978-79 school year wore on. There apparently was regular disagreement between school and home on the degree to which the school should tolerate disruptive behavior by Larry. The Corwins report that they were called numerous times during the year to take Larry home from school, or to be told of Larry's disruptive behavior: "every time he ran down the hall they were calling me to let me know how naughty Larry was, it was very aggravating." The conflicts between home and school apparently made life somewhat uncomfortable for Larry at school. The school staff felt increasingly that they were not able to meet Larry's needs.

Nonetheless, a report by Larry's EI teacher in March 1979 noted that Larry had "shown much growth since September." His ability to carry out academic tasks improved steadily; also his willingness to follow directions. It was noted that changes in routine were stressful to him. Also, he occasionally threw temper tantrums which he himself described as "the cowboys and Indians having fights inside." The report recommended that he continue his individualized program, but have more regularly structured opportunity to interact with peers.

The previous school year, late in the year, Larry's home district had reportedly withdrawn from its designated special educational regional grouping, which included the neighboring district in which Larry participated in the EMI program. That withdrawal, denying the district legitimate access to its neighbor's resources, plus an institutional desire to comply with the findings of the investigation of Larry's case, contributed to the decision to have Larry placed in a program in his home elementary school. Larry's home district rejoined its special education region during the 1978-79 school year. This made possible a train of events that brought Larry back to the neighboring district's EMI room, plus a newly created EI room, in March of 1979.

As has been reported, Jeanne and Richard Corwin were becoming increasingly upset with Larry's placement as the year wore on. In addition, the staff at his home school reportedly "discovered as they were working with him that it was just extremely hard to meet his needs." In late February the superintendent of his home district contacted the superintendent of the neighboring district, and asked if the latter would consider taking Larry back. An EPPC meeting was held, and Larry's parents were in favor of this move; in fact, they had stayed in touch with his EMI teacher, who they liked very much.

Observations in the School Setting

Historically, across different institutional settings, observations of Larry have suggested a fairly consistent pattern of behavior. When working by himself on a learning activity he requires a great deal of adult attention and support, but this support works only when Larry expresses a need for it; he prefers to work alone and privately once someone gets him started. Larry is easily distractible, and has trouble maintaining task attention. On his "good" days it is possible to get him back on task fairly quickly; on his "bad" days this is very difficult to do. He has been observed to be friendly and affectionate in his interactions with others; but he often wants to control interactions, so they take place on his own terms. He has, over the years, turned increasingly to a fantasy world, "tuning out" reality for long periods of time, and engaging in isolated play by himself.

Larry's feelings about school were apparently positive when he was four and five years old, began to become negative when he was six through eight years old, and are becoming more positive once again. Some comments of staff who work with him, and the observations of this writer, illustrate his current attitudes toward school and behavior in learning and social situations.

A student teacher who worked with him this year in the EI room has noted that "at first, I had to call his learning area play center, he had a strong reaction to the word learning, or the idea of learning tasks." This teacher has worked consciously on helping Larry deal more effectively with reality, and seen a lot of growth in this area. In the past, he notes, "Larry would use every tactic in the book to get out of interaction with other kids," though this too has been changing. At the moment that this writer was talking with the student teacher, Larry voluntarily went over to join a group of children working with the EI teacher for the first time all year. This was as enormous step, in their eyes, a goal they had been working toward during the year.

Larry's EMI teacher, who knows him best and has had the most contact with him since September 1977, talks about her first impressions: "Larry was extremely needy...initially he would totally break down at least twice a day, anything could set it off; he would fall apart emotionally and turn into this two year old... he could fantasize with anything, he could take a little square of cardboard and spend an hour playing with it... his behavior began to change very gradually, although progress was inconsistent; some days we could get a lot of work out of him, some days we were lucky to get 3 or 4 minutes at a setting..." Gradually the situation changed, as he saw consistent guidelines set for him. This year, Larry's behavior and response to school has steadily improved. Memory is still a central roadblock for him, "keeping things in his head." But Larry himself wants to work hard for the first time. This teacher noted that "frequently Larry is willing but emotionally unable to attempt things and engage other people."

This writer, in observing Larry interact with his EMI and EI teachers, feels that a major reason for his growth has been the warmth, constant support, and consistent structure they have supplied to his learning experience in school. Both are remarkable teachers, and his EMI teacher almost seems to "will" progress from him with her enormous commitment to Larry and the other children in that room.

His EI teacher has not seen a great deal of progress in Larry from her perspective; "he's basically been out of touch with reality much of the time he's been in this classroom." Improvement has come when an adult works with him one-on-one. She has been working with Larry on his ability to handle frustration, to attend to tasks, to be willing to negotiate, and

to work in groups with other children. She mentioned that he sometimes comes to class "with a lot of violence, which I think comes from television..." She has tried to make her agenda for Larry and his agenda merge, so the potential for struggle over control of the situation is minimized. This appears to have worked well.

Neither of Larry's two main teachers feel that he is ready to be mainstreamed for more than an extremely small portion of the day. In fact, his EMI teacher noted that the social gap between Larry and his age-mates has been increasing, and he is moving away from readiness to be mainstreamed. The question of whether he should go on to a fourth grade classroom next year is an open one, in her mind.

This writer recently observed Larry at school for three days.[1] The large part of his days is divided between the EMI and EI classrooms. Although he is part of a regular third grade class, he spends very little time with his class--mainly lunch, physical education, music, and art. Of a thirty hour week, he is with his classmates about five or six hours. Even when he is with them he appears to be socially very isolated from them, playing or working alone, shyly joining a group when asked to by a teacher. His friends are in the EMI or EI classrooms.

The following observations are typical of a broad array taken over a few days period:

In his EI room, Larry is observed to be distracted, and somewhat fearful. Upon arriving, he does not immediately settle down to work, but wanders over to some media equipment; he takes a pencil belonging to another child, and the teacher asks him to ask the other child if he can borrow it. His manner suddenly becomes distant, absent, unfocused. He looks in his desk, and sees no pencil. The teacher asks him if he'd like his own new one, trying to close the situation. The student teacher gets him to settle down with a math workbook. He works through the simple addition problems out loud; occasionally he'll get a correct answer but write it down incorrectly or in the wrong place. He appears to be working hard, though; episodes of concentration last about five minutes. It is observed that almost all of the work with Larry--academic work he can handle is used as a vehicle for working on socio-emotional goals--is in short episodes of about five minutes, for which he is then awarded a short break. As this writer was observing, Larry brought his workbook over to a table where a group of children was working with the teacher, and sat down with them. This was the first time he had voluntarily joined a group of children all year.

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[1]It is worth noting that it is extremely difficult to observe children like Larry who have many "teachers." Following Larry from setting to setting, while trying to remain unobtrusive, was very difficult.

In his EMI class Larry is observed working on language arts at his desk. He speaks out loud as he works in his workbook. The teacher comes over periodically to make sure he's on task, and to praise him for his correct answers. After about three minutes he gets distracted by a magnifying glass, and begins talking to himself about what he can do with it; he gets up, and begins playing with the glass near a window. The teacher brings him back to his work, telling him he can have a break in a few minutes. He does some more work using a timer to see how fast he can go. His teacher uses this as a tool to keep him on task. Larry is extremely aware of time, often looking at the classroom clock, saying that it is time for recess. Larry is easily distracted by other children, but seems to be able to get back to work with the assistance of the teacher.

II. The Five Major Provisions of the Law as They Relate to the Corwin Case

Protection in Evaluation Procedures

From the time of Larry's first evaluation at the local university hospital at the age of four, to the present, evaluations have been carried out regularly; reports have been sent to the Corwins; findings have been discussed with them; and no particular evaluations have ever been used inappropriately to determine placement for Larry. In general, appropriate tests and fully trained testers have been consistently used. Periodic administration of I.Q. tests have provided useful information for diagnostic and placement purposes largely because testers provided commentaries and behavioral analyses to accompany the quantitative scores.

Because P.L. 94-142 and Michigan's state law rely more on categorical labelling than functional labelling for classification purposes, much of the formal evaluation of Larry has been responsive to the need for categorical labels. Nonetheless, testing results have almost always been accompanied by other types of information (e.g., teachers' observations, parents' perceptions) at EPPC meetings. To the extent appropriate, multidisciplinary teams of evaluators have been involved in placement decisions. Finally, no single measure has ever been responsible for placement decisions.

The Corwins have not disagreed at any point with the results of an evaluation, and have found no reason to request amendments nor to ask for independent evaluations. Further, evaluations of Larry have been fairly consistent with one another, and in general accord with parental and teachers' perceptions.

The issue of the appropriateness of dual categorical labelling for Larry, leading to dual placement, is one that will probably remain unresolved as long as the causes of Larry's problems remain unclear. No one involved locally, including Larry's parents, appear to be overly concerned about Larry's dual placement. Also, evaluation procedures have generally been sensitive to both emotional and cognitive issues. Larry is also hearing impaired, but since he can hear well enough to function without a mechanical aide, this physical impairment has not been used as a primary categorical label describing Larry's handicap.

Procedural Safeguards

This provision of P.L. 94-142 appears to have worked reasonably effectively in Larry's case, within constraints imposed by a school system's refusal or inability to fulfill its commitments. In the fall of 1977, the Corwins' consent to Larry's placement in the EMI class of a neighboring district was based on a commitment by his home district to have an EI class in operation within a month's time. This never was implemented. Nonetheless,

at a number of points between 1975 and 1980, EPPC meetings provided a setting in which the Corwins and professionals involved in Larry's case could make quick decisions about changing his placement, or discuss well in advance future options.

In general, local educational agency officials have notified the Corwins in writing and on the phone well in advance of planned changes in Larry's program, and have given them a chance to respond. Within a context of considerable negotiation concerning Larry's placement over the years, Larry's home district and the neighboring district have both been very accommodating to the Corwins' wishes and complaints, and the Corwins have not had to resort at any point to an independent evaluation or a due process hearing (they were on the point of contacting a lawyer to begin due process proceedings for Larry's older brother, Robert, but they contacted an advocate who successfully applied pressure on the principal of Robert's school; Robert now has the special services he needs).

As far as can be ascertained, a regular, uniform evaluation and placement procedure has been followed over the years for Larry. There have been some changes in the make-up of Larry's EPPC, due to the changes in placement. But this appears not to have affected the decision-making process negatively.

Individualized Education Program

Considerable efforts appear to have been made in both of the two school districts serving Larry during the last three years to provide him with a detailed, well thought out Individualized Educational Program (IEP). The integrated private preschool program, and speech therapy program which he attended from March 1976 to June 1977 also engaged in extensive planning of goals for Larry, and implemented those goals to the extent feasible during the year. Formal, written IEPs have not been extensive and detailed; in fact, they have been very brief and telegraphic. But supplementary documents, including case studies, observation notes, evaluation documents, and informal plans, and evidence from interviews, indicates that teachers have had detailed, appropriately sequential plans for Larry, corresponding to his individual situation.

The private preschool, his home district, and the district where he now attends school all appear to have included (and implemented) evaluation plans as part of the IEP for Larry. Evaluations have been fully used for future planning, and well as for reviews of placement.

Least Restrictive Environment

This provision of P.L. 94-142 has proved to be especially problematic in its application in Larry's case. There has been, since Larry's first contact with the public schools, a continuous struggle concerning the appropriateness of educating Larry with non-handicapped children. Larry's home district was found by state compliance officials to be clearly in violation of state and federal law with respect to providing an appropriate placement for Larry. The district was, in effect, asking Larry and his parents to adapt to its situation, rather than adapting itself to Larry's needs. While Larry has had an opportunity to interact with non-handicapped children over the years, he has had, in practice, almost no interaction with them.

Ever since Larry entered the public schools, placement decisions have been made that could be viewed as more and more restrictive. Yet few of Larry's teachers or evaluators over the years have ever recommended a more fully mainstreamed program for Larry. Participants in EPPC meetings have consistently argued that it is, in fact, quite inappropriate for Larry to be educated with his peers. His EMI teacher has commented:

> "...as a special child becomes older, the gap between that child and his peers becomes greater; thus this issue (mainstreaming) grows in importance during the first few years of school...Larry is not moving toward being more ready to be mainstreamed; in fact he is moving away from it...it's not an academic issue, he gets that from me; but if he can't relate to his peer group at all, it's a frustrating, not growing, situation for him."

Larry's EI teacher not only concurs, but feels that a regular elementary school, even within a context of EMI and EI programs, may not be the best setting for meeting Larry's needs. It has never been the case that Larry is disruptive of other children; even with them in the same room he hardly interacts or socializes. He cannot function academically and socially in the midst of a large number of children. Also, he needs constant adult attention.

The Corwins have never pressed for Larry to be mainstreamed for a greater part of each day. But conversations with them suggest that they think that Larry spends more time with his regular class peers than he actually does. They do want desperately that he gain basic reading and writing skills, and thus support the intensive one-on-one attention Larry has in his EMI and EI rooms. But he is not, apparently, learning to function in the world of his non-handicapped peers.

The chronology of events narrated in the previous section of this case update suggest clearly that Larry's home district did not make an effort to provide Larry with the least restrictive appropriate placement during the 1977-78 school year. From the Corwin's perspective, though, the district

violated not only the letter, but the spirit of the law. As Mr. Corwin commented:

> "They told us that Larry's welfare is our primary concern at these EPPC meetings, and then the only thing they want to talk about is the welfare of the other children...they say we can't just do something for Larry and neglect all the other children in school...you can't seem to get across to them that we're here to talk about Larry, not the other children...at one meeting (Larry's current EMI teacher) slammed her fist down on the table and said to heck with the other children, Larry is the issue here..."

The formal investigation of the district's compliance in Larry's case revealed violations of the LRE provision during the 1977-78 school year. The next year, the district once again apparently tried to squeeze Larry into its existing services, thus causing both Larry and his parents aggravation. This was only ended when Larry returned to his placement in the neighboring district.

It is not clear the extent to which Larry's home district was willfully negligent, and the extent to which it thought it was acting in his best interests. Larry's situation has always been complex in terms of least restrictive appropriate environment. But the two districts involved in trying to meet his needs appear to have responded very differently: one expecting him to adapt to it, the other making every effort to adapt to him.

Parent Involvement

The Corwin's involvement in decisions affecting Larry's educational placement over the years has been strong in both extent and influence. All the educational agencies and institutions serving Larry have provided the Corwins multiple means and opportunities to express their concerns about Larry's needs; and all have been more or less responsive to those concerns. There was a problem during the first part of the 1978-79 school year, when Larry's home district wanted the Corwins to take responsibility for Larry's disruptive behavior at school, while they felt the school should handle it. This was probably part of the more general conflict between school and home. But the provisions of P.L. 94-142 appear to have been complied with in that and other settings. The Corwins have generally had a strong influence on programming for Larry, and are aware of their rights to participate in the educational decision-making process.

Thus, by the end of March 1979, Larry was back in his neighboring district, spending most of his time in the EMI and EI classrooms, participating with his classmates in his second grade class in physical education, art, music, and related activities. He also had regular speech therapy.

This arrangement, and Larry's dual classification, have continued during the 1979-80 school year, with Larry moving onto the third grade. His parents are extremely pleased with "things as they are." As Mr. Corwin has noted: "It's amazing the difference there can be just 8 miles down the road...they care; they don't talk to us about not having enough money, they say 'we'll find a way,' and they do it."

III. Major Issues in the Corwin Case

The major issues in the Corwin case appear to be those relating to least restrictive appropriate placement for Larry. For one thing, the causes of Larry's low level of cognitive and social functioning are far from clear. When this writer asked those professionals most closely involved with Larry what they think are the causes of his cognitive and social behavior, no clear answer emerged. There was consensus that he is emotionally impaired, and a very "needy" child. But the roots of this impairment are not known, or at least were not expressed to this writer. (In the near future attempts will be made to contact and discuss the question of causes and roots with the therapist Larry has begun to see.)

The question of most appropriate educational placement for Larry appears to have been resolved satisfactorily for the time being. But Larry is now ten years old, and the cognitive and social gap between him and his peers is growing. Progress has begun to be more consistent, but is still slow. Larry's teachers and principal care a great deal about him and are deeply committed to his success. They feel the need to ask, nonetheless, "are we doing enough for him?"

An important issue for over a year, now resolved and no longer affecting Larry, was the question of the degree to which a school district must adapt itself to the needs of an individual handicapped child. The State of Michigan, through its compliance division, found that a district is completely responsible for providing an appropriate education to any (and every) individual handicapped child, regardless of how unique that child's handicap is. In Larry's case, his home district appears to have dragged its feet, finally passing responsibility for Larry onto another district. Whether this pattern of institutional behavior was unique to Larry's care, or is symptomatic of broader policies is a question that this study unfortunately cannot address.

SEAN GILBERT

I. Introduction

Brief Case Sketch

Sean Gilbert was born in February 1974, the youngest of four children in the family of Louann and Roger Gilbert. Sean was a premature infant and at birth evidenced insufficient lung and liver development. He was kept in the hospital's infant intensive care unit for two weeks following delivery and his eyes were checked at two months of age for suspected eye damage. Sean, in infancy, also experienced a series of ear infections, and his mother reports he was slow to walk.

Today, Sean is an attractive six-year-old with a charming smile. He appears to be well-adjusted socially, interacting with his parents and siblings in a happy and casual manner. His mother reports that he is well-mannered and exhibits socially acceptable behavior in classroom settings, getting along well with his peers and teachers. This behavior is corraborated by evaluation reports from testers, the classroom teachers and was observed by myself in the classroom situation.

Sean has a swing to his walking gait which his mother will be checking on with the orthopedic doctor who is treating him. Sean also does not use both eyes together despite corrective surgery. He is supposed to be wearing corrective glasses but Sean does not like to wear them and, as a compromise, his mother only makes him wear them at certain times during the day. During classroom observation it was noted that Sean blinks in an exaggerated squinting manner. He did not have glasses on, or with him, that particular day.

Sean does not have a large vocabulary for normal conversation. He uses two- to three-word phrases to express himself, e.g., "Go store now?" He responds to directives very well and finger-points to identify objects, etc. It seems apparent to evaluators that his receptive language is at a much higher level than his expressive language. He also has been slow to toilet train but there has been a continuous effort of both school staff and family members to maintain a consistent pattern of training to assist him in this area of self-care. The past six months Sean has made significant gains in exhibiting more independence in taking care of his toileting needs, depending less on his peers and teachers for assistance.

Sean's mother Louann, is 35 years old and his father Roger is 38. He has a 14-year-old sister, 12-year-old brother and a 10-year-old brother. The Gilbert's live in a small village that sits on the edge of a little lake nestled in rolling countryside several miles from a city of any size. They are a hard-working family, making the best of limited resources. They are working together to build an addition and remodel their small frame cottage that is located on a quiet, shady, gravel street off the main road that runs parallel to the lake.

Louann Gilbert is a short, slightly built woman with medium-length dark brown hair. She is very warm and relaxed--an easy person to be with. She very obviously enjoys her family and presides over them with a very generous sense of humor, instilling in them a good deal of self-confidence as she encourages their independence as well as obedience. She works the afternoon shift at a small manufacturing plant, leaving for work at three each afternoon and driving over twenty miles to the plant, which is located in another little town.

Roger Gilbert, Sean's father, has been employed by the same plant for the past 16 years. It is located approximately 17 miles from their home. He is currently working the day shift which has worked out well for the family since Mrs. Gilbert is working the afternoon shift. He shows the same interest in family and home that Mrs. Gilbert does.

Sean's 14-year-old sister is quite mature for her age and takes care of the other children for her mother until her father comes home from work and then the father and daughter share the care of the boys. Sean's sister received speech therapy during the 1975-76 school year and her mother reports that she has been on the school's honor roll these past couple of years. Sean's brothers not only help around the house and property with chores, but are quite tolerant of having Sean tag after them and do things with them.

In summary, this is a very cohesive, happy family and Sean shares in the love and warmth that is spread by each member.

Chronology of Contacts with Institutions and Service Programs

In addition to his problems at birth, at the age of 14 months Sean suffered an attack of meningococcic meningitis and was hospitalized. He temporarily lost his sight, and was tube fed for three months in the hospital. When he was released from the hospital, he had reverted to a state of infancy and was unable to sit up, and was quite passive in his behavior. However, by fall 1975, when Sean was 19-months-old, he was sitting up again and his sight had returned to normal. After his recovery, doctors indicated that Sean had possible hearing problems, residual mental retardation and possible delayed motor development and visual functioning. Consequently, he was accepted into a university handicapped infant stimulation program at the age of 24 months.

In the spring of 1976, at two years of age, Sean was evaluated at a nearby university. Participants in this evaluation included staff from the fields of special education, social work, audiology, psychology, physical therapy, speech and dentistry. As a result of the evaluations, a recommendation was made to outfit Sean with orthopedic shoes and to provide speech therapy services for him; sight and hearing problems were ruled out by the evaluators. Sean was also kept in the infant program for the remainder of the year as a result of the evaluations.

From 1977 to 1979, Sean attended a private mainstreamed preschool program operated by an educational research organization. Transportation services for Sean were provided by the local school district to the private preschool program, which was located in a town some twenty-five miles from his home and outside his school district. In the spring of 1979, an EPPC meeting for Sean (he was five years old at the time) resulted in his placement in a self-contained center for the trainably and severely mentally impaired.

Since 1976 Sean has undergone corrective eye surgery and has had extensive dental work, resulting in the silver crowns he wears on his milk teeth. He is under periodic review by an orthopedic surgeon and wears corrective shoes. He continues to receive intensive speech therapy. It should be noted that Sean's siblings have also had speech problems, and have received speech therapy in their school setting.

Sean's first EPPC was held in October 1977 at the local school district's elementary school. (Mrs. Gilbert recalls that up until 1976 she had never heard of an EPPC. None of her other children had required anything but permission from her to have speech therapy through the local school district's speech and language therapist.) Mrs. Gilbert, the local school speech and language therapist, the regional special education director, the county public health nurse, local school district social worker, and two teachers from Sean's private preschool program were in attendance. Because there was no suitable preschool program available in the local district it was recommended that Sean stay in the private school program that his mother had enrolled him in that September. The local school district agreed to pay for the transportation to the private school's mainstreamed preschool program. Another recommendation was that Sean continue to receive speech therapy at the local school every two weeks. His program was scheduled to be reviewed again in April of 1978 unless his own school district was able to provide a suitable program before that time, at which time another EPPC would be called. Mrs. Gilbert was in agreement and there were no problems surrounding this EPPC.

The second EPPC was held as scheduled in April 1978. The composition of that EPPC committee was the same as the 1977 one. The recommendation was that, since Sean's local school district still had no suitable preschool program, he should remain in the private school. His school district would continue to pay for his transportation. It was agreed that Sean's school case would be reviewed again the following April unless Sean's school district came up with a suitable program in the meantime. Again, there were no problems surrounding this EPPC.

The third EPPC was held as scheduled in April 1979 at the county intermediate school district's Trainable Mentally Impaired-Severely Mentally Impaired Center with their staff, Mrs. Gilbert, two teachers from the private school, and the special education director from the Gilberts' area. The options offered Mrs. Gilbert this time were the choice between keeping Sean in the private school or placing him in the TMI-SMI Center that month to finish out the spring term. Mrs. Gilbert chose to place Sean in the TMI-SMI Center's preschool program, called pre-primary.

She based her choice on the fact that Sean would be able to receive a more extensive speech therapy program as well as participate in other activities such as the pool, gym, etc. He would also be in school five days a week instead of four. The Gilbert's local school district still had no option to offer the Gilberts so Sean's transportation to the center several miles from his home was provided by his local school district once again. (Mrs. Gilbert reports that the local school district has promised to develop a program that Sean would qualify for at his own elementary school when at least six qualified children can participate.) Mrs. Gilbert was satisfied with the outcomes of this EPPC also and has had no problems with the procedures since then.

Mrs. Gilbert also reported that the private preschool's classroom teacher was upset by her decision to place Sean at the TMI-SMI Center because the teacher felt Sean was too advanced for their program. Mrs. Gilbert said, "You know, she was so upset that she cried." She reports that she has been satisfied with Sean's performance and feels she did not make an unwise choice. But such behavior on the part of professionals who are dealing with parents during a time of decision-making might well trigger a sense of confusion and guilt for the parent regarding the decision they finally make.

Sean's current educational setting is the aforementioned center for TMI-SMI individuals. The center is run by an intermediate educational agency, and serves people from the entire county; services are provided there from birth to age twenty-five. Its facilities are modern and comprehensive at all age levels, and include a full range of both evaluation and therapeutic services. Although some of Sean's former teachers objected strongly to his placement there, feeling at the least that it was too soon to tell if Sean would eventually need services at the TMI level, Sean's mother feels he can get the full range of services there that he needs now, and in no way sees his current placement as permanent. It should be noted that Sean's current teachers express this same outlook and have requested a new evaluation this spring.

Observations Within the School Setting

The latest observation of Sean took place in the primary (K-7) classroom within the special education TMI-SMI Center in February this year. The children were gathering around the table with teacher and aide for a language session. Fifteen minutes were spent on the letter L using pictures and printed words starting with L. Sean quickly seated himself when the teacher aide summoned the children to the table. He smiled, laughed and interacted in a friendly manner with the others at the table. He kept his eyes on the aide responding to the cues to repeat words or identify pictures. His identification of pictures was accurate, but the aide would need to remind him to use "l" rather than "w," e.g., "leg, l, not weg, w, Sean." He was not wearing the corrective glasses and it was observed that he exhibited an exaggerated hard blinking periodically during this exercise.

For the next fifteen-minute period the children were asked to draw lines between matching pictures (and words) beginning with "l," e.g., lamb, leaf, etc. The teacher aide was also stressing the left-to-right process in drawing the line. It was noted by this observer that the children also had the appropriate letter printed by magic marker on the tops of their hands. It appeared that Sean was not quite sure of what was involved in accomplishing this task. He would study his own paper quite intently for a few seconds, attempt to draw a line (without matching appropriately), observe the teacher working with other children, then make another attempt to draw a line. He was using the left-to-right process about half of the time but not getting the lines complete nor was he accurately matching the pictures. The teacher then proceeded to give Sean individual attention and assistance. However, when she left, he did not continue the activity in an appropriate manner. He began drawing circles and reversing the pencil from the appropriate way of holding to a full-hand grasping method, holding the pencil in straight-up position. The teacher handed out cut-outs in the shape of lollipops for the children to take home for parents to see the use of "l" was being worked on that day. After this exercise the children were told it was time to get their clothing, pick a spot in the room and get ready for the school buses.

Sean seemed to need a good deal of prompting to "get into" the preparation process necessary for getting ready to go home. In fact, the observer timed Sean and it took him 22 minutes, much encouragement and reinforcing from the teacher and teacher aide to finally get into a snowmobile-type one-piece snowsuit, boots and mittens. He would yell for the teacher aide not to read a story (by the door) until he got there, but would make no attempt to hurry the process of getting on his boots by himself. Once the task was finally completed he still stopped at the sink, made some observation and was reminded by the teacher that the story was going to get started if he wanted to listen.

After the children left, the teacher and aide answered the observer's questions and discussed the areas of greatest development for Sean this school year. His expressive language is improving. He puts more words together and uses more words on an overall basis. He receives one-half hour of speech twice a week. His small motor development is still lagging in some areas, e.g., pencil-holding example. Sean's greatest improvement is in the area of self-help skills. He is becoming more independent, and is turning away assistance by staff and peers more frequently in areas of personal care such as tooth brushing, toileting, etc. In the past couple of weeks he has begun dressing himself for the trip home with less actual physical assistance from teacher and peers, but does need a good deal of verbal encouragement, reinforcement and reminding.

II. The Five Major Provisions of the Law as They Relate to the Gilbert Case

Protection in Evaluation Procedures

Sean has been seen by both medical and educational specialists during most of his life. He has had two major series of evaluations, at age two and four, to determine the extent and nature of his handicap and to determine his most appropriate educational placement. These tests were conducted by staff at the university program and by the intermediate educational agency's center for TMI children. Evaluations appear to have been individually designed for Sean and fully comprehensive; certainly, Mrs. Gilbert feels very comfortable with the way in which they were conducted and with the information they yielded about Sean. Evaluations and evaluation procedures, in other words, have not been an issue in the Gilbert case, nor have the protection provisions of the law been required for Sean in his parent's view.

As with most of the other families in the study, the Gilberts feel comfortable in their associations with professionals. Mrs. Gilbert has been closely associated with the university hospital, and has used its services extensively for her family. It was through the hospital staff that she became acquainted with services for handicapped children in the area. Another strong influence for Louann has been the county-visiting nurse, who participated in Sean's first EPPC and was instrumental in linking Sean's mother up with the private preschool program. In other words, the Gilberts are accustomed to asking for help and getting it. Such steady support and guidance have undoubtedly helped Mrs. Gilbert accept the results of the evaluations of her son. In interviews she displays an unusually relaxed, accepting attitude about her son's limitations. This attitude, however, is not to be confused with apathy, for Louann definitely feels she is actively involved in ensuring that Sean receives proper evaluation and attention, and the best educational placement possible.

Procedural Safeguards

As has been recounted earlier, Sean has had three EPPC meetings, to which the Gilberts have raised no objections and with whose conclusions they have heartily agreed. In other words, the somewhat isolated rural school district in which the Gilberts live has shown, since 1977, an intent to conform in letter and spirit to the state (and Federal) law in the Gilbert case, and the procedure has operated to the Gilbert's satisfaction.

It appears that up to the present the provision relating to procedural safeguards has had a strong and positive impact in Sean's case. Part of this positive impact has been due to the essential agreement between all participants as to what needed to be done for Sean, and to Mrs. Gilbert's basically accepting attitude. But there is also a small-town, neighborly flavor to the way in which placement recommendations have been considered

and supported (in contrast, say, to the sometimes harsh conflicts of the Kingsley case, also occurring in a small town in the present study). The school district has been willing to go out of its way to provide transportation to the private preschool program (a station wagon and driver to pick up Sean and drive him to school and pick him up again), because that was the most appropriate placement for him. This instance reflects a sense portrayed in the EPPC documentation and in Mrs. Gilbert's recollections of the procedures followed, that the intent of the law to consider Sean's individual needs and recommend what might be best for him was implemented in his case.

Individualized Education Programs (IEPs)

Again, there appears to be no question that programming for Sean (both in terms of the selection of program options and of their implementation) has been appropriately individualized. Although individualized education plans were not formally written out for the school district by the private preschool program in 1977-79, the preschool teaching staff used their own version of instruments for developing and assessing goals and objectives for Sean, and discussed their plans and Sean's performance with the parents, both in school and through periodic home visits. At the current setting in the TMI center, one IEP was developed soon after Sean entered the program, and Mrs. Gilbert participated in its elaboration. Louann understands that IEPs have become a standard procedure for Sean; she feels they will help her understand what the "experts" are doing with her child, and what kind of progress he is making. As long as she continues on the afternoon shift where she works, she will be able to attend meetings. She has observed Sean in his current classroom and is content with the curriculum and Sean's obvious progress.

The law, in short, appears to have had positive impact in producing appropriate individualized programming for Sean to date.

Least Restrictive Environment

To this point, the LRE provisions of the law have not had much impact on Sean's case, principally because few services (only speech therapy) have been available for Sean in the local educational agency. On the other hand, local school staff have been willing to support the provision of most appropriate services for Sean outside the local area.

Due to the lack of appropriate programs in his own school district, Sean has been serviced by programs located a considerable distance from his home. There was not much available to the Gilberts, or so it appears from hearing Mrs. Gilbert recount the history of events. She was referred initially to the infant program by the doctors at the university hospital when Sean was two years old. She was referred to the private preschool, which had a mainstreamed program, by the county-visiting nurse. She has not really

questioned whether or not the placements were in the least restrictive environment, but whether, in fact, they would be available to Sean at all due to the distance between home and the programs. She began the school year in September of 1977 by driving Sean about 20 miles to the private preschool and stayed until it was time to bring him back home, and continued to do this until the EPPC in mid-October, when the local school district took over the transportation both financially and operationally.

Mrs. Gilbert seems somewhat uncertain as to what the local school district is doing about planning its own program for children like Sean. As far as the LRE provision relates to Sean, it appears at this writing that the local school system is not offering any options to choose from and the mother has decided to stay with the TMI classroom. A major issue will arise if Sean makes considerable gains that will put him beyond the range of the TMI setting, into a positively identified EMI range. The least restrictive environment may at that point become an issue given the lack of services at the local school district level, unless the district does develop some programs in the meantime.

Parental Involvement

There has been no breach of any of the requirements under this provision in the Gilbert case. The Gilberts have not felt it necessary to refuse consent for placement and they have been notified of and included in all EPPC and IEP meetings, as well as the evaluation meetings and other meetings relevant to Sean's educational placement.

Mrs. Gilbert's involvement outside of the actual placement meetings is perhaps reflective of the rural area in which they live. She volunteered to serve on the school district's parent advisory committee by the local school district special education director. She stated that the purpose of the committee was to attempt to monitor what is going on in the way of programs and decisions in relation to the handicapped children in their area. Mrs. Gilbert was also informed by the local school district special education director of an advocacy training program being conducted at the county intermediate school district offices. The advocacy program was funded through a local university program. Mrs. Gilbert felt at first that she did not need to take the course because she had not experienced any problems and did not know anything about laws, etc. But, in retrospect, she is glad she knows what is going on and what she can do about it. Mrs. Gilbert was not certain about how much she actually learned from the training course, but it became apparent during our interview that she would know how to obtain services for Sean even if she moved to a strange area.

> "Well, I didn't have any problems getting him into school. Then they--in those classes--talked about people having all these problems. I thought--God, I never had any, I wonder what they are talking about, you know? I assume it would be very helpful to a lot of them because, well,

some need it more than others. Some school districts are squabbling, some don't provide as much as others, some don't have it (placement) and some act like they don't want to provide it."

Mrs. Gilbert's sister lives in the northern part of the state and has shared information concerning the difficulty of obtaining special education services in that sparsely populated area. Mrs. Gilbert stated:

"We'd like to go up north and live, but I don't think he'd have the benefits that he has here--you know--the little one (Sean). I'd have to go up there and wage war. I have a funny feeling I would have problems. They'd probably wish they had never heard of me."

III. Major Issues in the Gilbert Case

In the preceding sections of this document, the relevant impacts of the law and related issues were documented for each of the five major provisions of P.L. 94-142. This section presents another way of looking at notable features of the Gilbert case, features that cut across the major provisions and highlight areas in which adherence to the spirit or intent of the law does not necessarily equal adherence to its letter. These areas also represent aspects of the present case that the researchers will continue to follow up and explore in greater depth in the future.

Ongoing Placement

Several issues in Sean's case make his ongoing placement uncertain. For instance, the local school district promises to design a program that Sean will "qualify for" if there is a large enough number of children. It is not certain that Sean's premature birth and later case of meningitis is the sole cause of his developmental lag. He is now six years old and has time to outgrow some of these lags given the uncertainty of his prognoses. He is already showing gains in language acquisition, self-help skills and independence. His classroom teachers are requesting a re-evaluation this May to determine the extent of his progress and what it means in the way of placement for Sean. It is not apparent if this re-evaluation will place Sean into an EMI setting or simply move him forward at the TMI center he currently attends. How Mr. and Mrs. Gilbert view any progress or significant changes in Sean's development and subsequently, any needed changes in his placement will be of major importance to this case and will be reported in a future update to this case.

Facing the Reality of the Child's Handicap

Sean is a very attractive little boy and the baby of the family. In the next few years he will outgrow the cherubic look and nature that he has now, however. And, while his siblings have had speech problems, but no other obvious handicaps, Sean's prognosis is more uncertain. If he doesn't make significant gains, his family will have to deal with the reality of his handicap. Right now, it is difficult to make any judgments about this family's future attitudes because of all the uncertainties involved. But this does appear to be a very resilient, non-flappable family used to making the best of things and moving on.

Economic Costs

To date, Mrs. Gilbert has been an astute consumer of services needed. The Gilberts have had no undue expenses in relation to Sean's education up to this point. In fact, Sean's placement in the five-day public school TMI center has made it possible for Mrs. Gilbert to return to the work force.

PATRICIA OLIVER

I. Introduction

Brief Case Sketch

Patricia was born in May 1973 to Tracy and William Oliver. Tracy was 16 and William 18 at the time of Patricia's birth. Tracy's pregnancy was complicated by maternal toxemia in the last trimester, but the delivery was normal. At birth, Patricia evidenced both signs of multiple congenital anomalies and organic disease. It was clear from birth that she would have special medical and educational needs; and, as her case has developed, this early prognosis has been confirmed. Over her six years of life, Patricia has been through three major operations, a host of examinations and evaluations, and has had intensive service involvement by different professional groups.

Patricia's family life has also undergone several disruptive changes over the past six years. Her biological father, William, had grand mal seizures which Tracy feels played a major part in his exhibiting serious temper flare-ups. It was during one such flare-up that he tossed two-month-old Patricia against a wall and threatened Tracy with a knife. This event resulted in Tracy taking Patricia and returning to her parents' home, and ultimately ending the marriage to William. While Patricia did not suffer any real physical damage from this treatment, Tracy says, "I will always wonder what that did to her emotionally." Tracy stayed with her parents for over a year. After her mother's death in October 1974, Tracy married for the second time, took Patricia and moved to a southern state with her new husband. However, this marriage was short-lived also and Tracy reports she was back home in a month and moved around a lot until she married Kevin Lambert three years later.[1] Tracy describes this period in her life as "mixed-up and confused, unsettling for me and for Patricia."

Tracy and Kevin have two young sons born in 1977 and 1979. The oldest son has problems with seizures when he suffers a high temperature. He was on phenobarbital for a year. The youngest son had some bowel problems during the fall of 1979 but is now fine. Kevin Lambert, at 23 years of age, is a very concerned and supportive person who has shouldered the burden and responsibility of Patricia's care and treatment equally with Tracy. He is also quite comfortable in the care and nuturing of the infant and toddler. Until the recent rash of lay-offs at the local automobile manufacturing plants, Kevin was employed on a production line at one of the small parts plants. Since his lay-off Tracy has signed up at their local school district's transportation office as a substitute bus aide on the special education bus route.

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[1]Throughout the case study, Patricia will continue to be identified with the last name of Oliver, as her step-father, Kevin Lambert, has not formally adopted her. Her mother and step-father are identified as the Lamberts.

While the Lamberts have not had the benefit of a sound, permanent financial status, they have not had to absorb a great deal of the medical or other expenses relevant to Patricia's handicaps. They moved from their mobile home this winter into a small, compact, neatly kept bungalow just a short distance from their former neighborhood. Kevin stated that this house belonged to his family and he grew up there. Patricia appears to have adjusted to this move quite well; as Tracy said, "One thing she's used to is moving." This couple have little in the way of respite care for the three children. It is difficult to hire a sitter who is willing to take care of a child who is handicapped, let alone add two more under three years of age. This means that Tracy and Kevin are confined at home, rarely able to get away without the children. Lack of funds due to the current lay-offs simply compounds this young family's problems and frustrations. Given these circumstances, the warm and loving environment experienced while visiting in their home is considered to be remarkable by this observer.

A Chronology of Contacts with Institutions and Service Programs

A description of Patricia's physical condition at birth, as described in the report from the Department of Pediatrics at the hospital where she was born, will allow the reader to more fully understand the extent of this child's handicaps and resultant chronological history. In spite of the complications the mother exhibited during pregnancy (toxemia and vaginal infections) the delivery was uneventful. An apgar at 1 and 5 minutes read at 9.

The infant was examined in the newborn nursery with the following conditions being noted: estimated gestational age, 40 weeks; weight 6 lbs. 14 oz.; transient hypoglycemia requiring supplemental infusions of glucose; ears bilaterally low set with marked right ear deformity, lacking both in cartilage and soft tissue structure, external auditory canals covered, but both canals present; left ear affected but to lesser extent; shape of head was rather unusual with marked asymmetry and flattening of the posterior right side; eyes were microthalmic in nature; hypoplastic thumbs bilaterally; syndactyly of the second and third toes bilaterally.

Within 21 hours of birth Patricia developed hyperbilirubinemia and was treated briefly with phototherapy. She was also treated with penicillin and kanamycin for suspected sepsis. During the following six days she was seen by Neurosurgery for possible encephalocele (which was negative); plastic surgery staff to evaluate the ear anomalies (recommendations to follow and re-evaluate in one year) and a chromosome test was run (46 xx Karyotype with an unidentified extra fragment). At age seven days, she was discharged from the hospital.

On June 29, 1973, Patricia was admitted to the hospital at five weeks of age with a diagnosis of right upper lobe pneumonia and bilateral conjunctivitis. A cardiovascular examination revealed a systolic murmur and a diagnosis of congenital heart disease. She was released on the fifth day.

Much of what happened to Patricia over the following year had more to do with the upheaval in her mother's life. Tracy says that other than routine doctor's appointments, she attempted to deal with Patricia's problems on her own. She recalls that Patricia could not hold up her head, sit-up, crawl or move on her own. Tracy tried exercising Patricia's arms and legs and when she was not attending to her, Tracy's mother, a nurse, was. By the fall of 1974 Tracy was propping Patricia in a walker. So, at a year-and-a-half, she was sitting propped and began using her feet and legs to propel herself while in the walker.

At the recommendation of the doctors at the eye/ear/nose and throat clinic, Patricia was seen by an optholmologist and he prescribed eye patches to remedy the weak eye muscles which prevented Patricia from using the eyes together. Tracy says she did this for "about a year, then quit as it was a hassle and she seemed to be better." It was also during this period of time that Tracy lost her mother after several heart attacks, and she married and divorced for the second time. It was obviously a gray period for both mother and child.

At the age of two (in July, 1975) the university's audiology department conducted an examination of Patricia; the results showed moderate hearing loss on one side, and moderately severe loss on the other. Because her visible anomalies included deformities in both ears and cranial flattening on the right rear side, the specialist referred Tracy to the local chapter of a society for helping crippled children to explore the possibility of providing Patricia with a bone conducting hearing aid. Meanwhile, he recommended trial amplification and continued testing, speech therapy and further examinations by an otorhinolaryngologist and an opthalmologist. Speech therapy had already been initiated by another department at the university in January of 1975. Problems in gross motor coordination, eye contact and both receptive and expressive language were identified during this time and were being worked on in therapy. On the basis of recommendations by the speech therapist, the family was enrolled in an infant stimulation program run by the university that had a home visit component. It was unfortunate that no home visits were made during this program due to the unsettled state of Tracy's personal life. They did develop a home program for Tracy to work on between the speech therapy sessions. Patricia was to attend the therapy sessions at the university four days a week, two hours a day with one and one-half hours involved in a group situation and one-half hour on an individual basis. The final summary prepared in December by the speech therapy staff cited excessive absences and lack of home visits as a problem in treating Patricia.

There was little evidence of visible improvement in expressive language, although Patricia give signs identifying some common object nouns and interpreting some verbs correctly. She would stare at shiny objects for long periods of time but not make eye contact with the therapist. Tracy maintained that this speech therapy was not enough, that Patricia needed more.

"They just kept doing the same thing over and over, no wonder she wasn't really learning anything new."

In March of 1976, when Patricia was almost three, the university tested her once again. Based on these tests, Patricia received the first stage of corrective ear surgery in April. The plastic surgery would create an ear that would allow the support of a bone conductor hearing aid. By late fall of 1976, Tracy had made a decision to put Patricia in a preschool program. She talked with the director of the local school district's preschool program and the local special education director, and was referred to a local private mainstreamed preschool program. She enrolled Patricia in this program for December of 1976.

The local school district conducted the first EPPC meeting for Patricia in March of 1977. As the records show, placement for Patricia was not the issue at that meeting. The discussion of the group in attendance centered on clarifying goals for the child and on strategies for meeting these goals and evaluating progress. Speech therapy continued, but progress was extremely limited; little adaptive change was noted in Patricia's behavior in the private preschool program. Because of further impending surgery (and the possible changes it might make in Patricia's life and behavior) and because of the need felt for further evaluation, the committee's main recommendation was to meet again two months later. In April of the same year, Patricia went into the university hospital again for corrective heart surgery. Complications forced a long stay and a return to the hospital three weeks later. In June, extensive medical tests on Patricia's postoperative situation were conducted, leading to a diagnosis of subaortic stenosis and a recommendation that Patricia's physical activity be strongly limited upon any signs of fatigue, with a further recommendation for prophylactic use of antibiotics in case of any future major medical or dental intervention.

The university hospital's psychology group conducted a psychometric evaluation of Patricia in June 1977 (age: four years). The evaluation showed Patricia to be functioning overall in the moderately-to-severely impaired range of intelligence, and produced the recommendation that she be placed in a self-contained environment for retarded children. In spite of this recommendation, Patricia continued in the mainstreamed private preschool setting during 1977-78; the preschool teachers and Patricia's mother agreed that the setting deserved one more trial.

A second EPPC meeting for Patricia was held in the spring of 1978 by the intermediate educational agency's facility for trainable and severely mentally impaired children, following upon an evaluation by that facility's staff of Patricia's needs and capabilities. Speech therapy services had again been provided in 1977-78, and again showed progress to be limited. The teachers at the private preschool program, meanwhile, had noted that Patricia required more individualized special attention than they could reasonably provide in a mainstreamed environment, and that some of the other children in the environment were beginning to react toward Patricia in an increasingly stereotyped way (mothering her and treating her as a baby)

that was not helping her grow. A unanimous recommendation resulted from the meeting that Patricia be placed in the center of trainable and severely mentally impaired children. Upon Tracy's agreement, this recommendation was carried out.

Patricia is currently (March, 1980) placed within this center in a pre-primary program where she receives speech therapy, physical therapy and a range of other services for the whole school day, 9:00-2:00 o'clock. She is bused to and from her home to the center. In December 1979, Patricia was seen by the cardiologist who feels she is doing well and should be limited only by her level of fatigue. In February she was seen by the opthalmologist who said the eye muscles have strengthened and it appears there will be no need for corrective surgery. He did request that she be checked every six months until she can respond verbally to the tests administered. During the second week of March, Patricia was seen by neurologists at the Pediatric Neurology Clinic of the university hospital. She was given an EEG and an EEG-Barre. To date, we only have the results of the EEG, which offered evidence of slight brain damage. The two doctors, according to Tracy, stated that Patricia evidenced some autistic behaviors and have put her on two milligrams of valium a day to decrease her hyperventilating and hyperactivity. They also suggested that Tracy try to discover what anti-nausea drug she was taking during the first weeks of her pregnancy.

During a conversation with Patricia's classroom teacher, she stated that she and the speech therapist requested a re-evaluation of Patricia's hearing with the thought of an EPPC this fall to determine the appropriate placement for Patricia, such as a total hearing impaired program or a shared time program. She feels that Patricia is showing signs of progress and it is time to reassess her abilities and possibilities. At best, it is difficult to determine the least and the greatest of her handicaps given all the circumstances surrounding her brief six years and nine months of life.

Observations in the Classroom Setting

Patricia was observed in December 1979 during music physical therapy, group activity and snack time. The classroom teacher spent time with the researcher describing the purpose of all the activities observed, the goals set for Patricia and the gains they felt she had made. Patricia at no time initiated any interaction with the other children. She needed a good deal of prodding and encouragement to get involved but appeared to enjoy the music. Some signing was used by the staff but I did not see Patricia use it consistently. She used no real words during the entire morning. The teacher reported that Patricia has gained a vocabulary of 6-10 words which she uses spontaneously, but will not repeat or use them to respond to the teacher's questions. She does respond to verbal directions. The teacher said the signing is a supplement to language development. During the physical therapy she laughed and squealed while swinging (which seemed to be her favorite activity). She was made to sit down and rest periodically. After each activity she would sign something.

Back in the classroom the teacher said Patricia seems to know when it is snack time regardless of where she is and that she had been signing "cookie." Being in a structured setting for the school day (9:00-2:00) appears to be having the hoped for impact. She makes eye contact more often and for longer periods of time, she is going toward people more often and is beginning to interact with her peers when they initiate it. She is beginning to produce words. The biggest issue is: should Patricia be in a hearing impaired program or a shared time program? It is difficult to draw any cut and dried conclusions. Based on a half-day observation, however, and compared to written reports from past programs--Patricia is definitely beginning to reach out to the world around her, although cautiously.

II. The Five Major Provisions of the Law as They Relate to the Oliver Case

Protection in Evaluation Procedures

Insofar as available information permits, our current assessment is that proper evaluation procedures have been followed, and that evaluation results were used in Patricia's placements. The parents have been present during the many evaluations and the results have been discussed with them. The main burden of evaluation for Patricia from 1973-1977 has been carried by the various clinics contained within the university hospital. The one exception is evaluations of speech therapy sessions from 1975-1977 conducted at another university's speech and hearing clinic. In 1978 and since, the intermediate school's educational agency for TMI/SMI children has conducted its own assessments, and has also requested that the parents have outside evaluations conducted.

Tracy and Kevin have done their best to keep appointments for the needed evaluations, the majority of which have been medical evaluations related to Patricia's eyes, heart and hearing problems. The most recent evaluation was conducted at the university hospital's pediatric neurology clinic on March 10th at the request of the school's speech therapist and classroom teacher. Patricia was given an EEG and EEG-Barre test. These evaluation results will form a major part of the basis for determining Patricia's placement in the least restrictive environment this fall.

Tracy has signed release of information forms for project staff to submit to the various medical and educational institutions to obtain the records necessary and relevant to the case study. It is our opinion that insofar as we can determine their rights to confidentiality of records have not been violated. It is apparent, however, that Tracy and Kevin have not attempted to request any of the records, nor were completely aware of their rights in this matter. In a late fall 1979 interview, Kevin Lambert asked,

> "What rights do I have? We've got a right to walk in that school and look at her records, right?"

He was unsure as to who had the right to decide when Patricia should be tested again. Obviously, both parents were unaware that they also had the right to request amendment of these records.

Procedural Safeguards

Patricia's case is another in which involvement with evaluation and service organizations have been extensive since birth. Identification of Patricia as a child with special needs was not an issue either for the parents or for the local school district; nor was placement an issue in the

first EPPC in early 1977. By the time Patricia's first EPPC meeting occurred, she had already been receiving services for almost two years through the university hospital and the speech and hearing clinic's infant/toddler program.

We continue to gather new information each time we contact Patricia's parents, especially Tracy, who will remember some other aspect of Patricia's problems or services she received as we raise new questions concerning the case. As a result, documentary evidence supporting these issues continues to come in to our office. We will continue to add new information at each case update. Our sense, to date, is that procedural safeguards to placement and parental involvement do not appear to have been at issue in Patricia's case so far.

Individualized Education Plan

A good deal of Patricia's case fell outside of the legal requirement for written individual education plans until 1977. The university placement in the speech and hearing clinic's infant/toddler program in 1975, as well as the private preschool placement in 1976-1978, were situations in which no educational agency required written IEP records. The first direct involvement of a public school occurred in 1977, well after the initiation of service delivery. The speech clinic developed a set of goals for Patricia and implemented intensive speech therapy sessions as well as home program component for Tracy to carry out between sessions at the clinic. Records available from the private preschool program show that teachers there used that educational organization's own goal and objective-setting instruments to plan activities for Patricia in a highly individual way.

The records for the 1977 EPPC show that creating an appropriate goal-set suitable for Patricia's needs was a central concern--again, evidence of individualization in attempting to make decisions concerning Patricia's education. This EPPC was conducted with staff from the private preschool, speech and hearing clinic, TMI/SMI center and local school district special education director.

Since the change of placement to the self-contained TMI/SMI setting in 1978 (when Patricia was five), IEPs have been developed by the classroom teachers, speech and physical therapists, with goals being planned and discussed with Tracy.

The available evidence, then, suggests considerable efforts were made by the various professionals and service organizations involved in Patricia's case to provide individualized educational programs for her and for her family. Initially, this individualization was at least partly due to the unique nature of her case and her highly specific needs. The impact of the law can best be seen in this case in the explicit conduct of a major review

meeting aimed at defining goals for Patricia, and in the nature of attempts since that date at fulfilling those goals and at preparing new IEPs for Patricia. We would judge that the impact of this provision of the law is substantial.

Least Restrictive Environment

Proper placement in the most appropriate and least restrictive environment is likely to be the principal issue in this case in the future, although Patricia's situation has not yet reached a sufficiently stable determination to be able to tell. Certainly, Patricia's current placement is most appropriate for her considering the availability of services in the area in which she lives and current diagnosis of her educational potential; and Tracy and Kevin, overall, approve of Patricia's current setting. But, as has been mentioned before, Tracy feels that once Patricia learns signing (which has been a major thrust of her most recent IEPs) and settles into the use of her hearing aid, she will make more rapid progress in communicative skills and in her overall development. Kevin, for his part, feels that she would get more out of her current placement if she could attend full-day instead of half-day sessions.

Up to the present the most appropriate placement for Patricia has not been an issue. Given the extensive nature of her medical problems, she has had attention in clinic and therapeutic settings, home visits, in a mainstreamed preschool environment and in a self-contained TMI classroom facility. These various options have been tried as long as they seemed appropriate, and decisions to attempt other options have received the support of all participants. The law has helped by providing a forum, since 1977, for joint consideration of the options available for placement. In summary, this provision has been adequately fulfilled in Patricia's case up until the present: a continuum of placement options exists and has been tried; reviews of placement have been properly regular; and mainstreaming options have been tried. That this has not been a major issue in the present case is due, in some part, to the fact that the local and intermediate educational agencies have provided a forum for consideration of her case and for making decisions about option selection. It may become an issue in the future.

Parental Involvement

Patricia's mother and step-father display warm and loving concern for their child, and show every sign of being involved in her development. In terms of the letter of the law, as far as currently available information permits us to estimate, Tracy has participated in EPPCs and IEP planning. The private preschool program included home visits and periodic consultation between teachers and Tracy; she recalls reviewing the IEPs developed at the TMI/SMI center that is Patricia's current placement, producing copies for project staff to review also.

Both the law and the attitudes of some of the professionals involved appear to have had a positive impact in giving Tracy and, more recently, Kevin, an opportunity to be involved in the decisions regarding their child's placement and the implementation of an educational program for her. They are just recently becoming aware of their rights in relation to these issues.

III. Major Issues in the Oliver Case

In an earlier section of this document, the impacts of the law were documented and discussed for each of the five major provisions of P.L. 94-142. This section presents another way of looking at notable features of Patricia's case, features that cut across the major provisions and represent aspects of the case that will be explored in greater depth in the future.

As with a few of the other cases in the present study, the situation of Patricia Oliver is still very much under development and cannot be said to have reached stability. The impact of the law in the current situation of Patricia can be defined, but it appears likely that there will be other impacts.

Our analysis of this case, likewise, is still somewhat tentative. Rapport, however, is excellent and we expect to update data collection as Tracy and Kevin are able to meet with us and continue to share the issues surrounding Patricia's educational needs.

Ongoing Placement

Patricia's mother maintains that her child's true potential is still an open question. It is true that adjustments are still taking place that could strongly affect assessments of Patricia's capacity to develop; if she makes favorable adjustments to her hearing aid and develops signing skills, her placement could change radically. Ongoing placement and Patricia's adaptation and performance in her current setting are continuing to be the foci of investigation for the study.

Tracy exhibited ambivalence in her feelings about Patricia's placement at the TMI/SMI center in a conversation in November 1979.

> "You see, the school she is in is not for the hearing impaired. She is in a school for the mentally retarded and mongoloid. I think she is in the right place, but I think she would have caught up a long time ago if they would have taught her the right things at that speech clinic program. Sometimes I wonder if people are ever going to listen to me. She is not retarded. I think she is behind because of surgeries and everything. She should have had proper placement when she was younger, but they (speech clinic staff) wouldn't listen to me."

In June of 1977, at four years, one month, Patricia was evaluated at the university hospital pediatric psychology department. Using the Cattell Infant Intelligence test, she was diagnosed as a moderate to severely retarded functioning child with a mental age of 1 year, 4.8 months. This

diagnosis was discussed with Tracy, according to the report. Kevin stated Patricia had also been seen by a neurosurgeon who said she had autistic-like behavior. He recalled seeing a special on television about autistic children who spun plates. Tracy said that Patricia used to do the same thing.

Ironically, the doctor involved in administering the EEG to Patricia on March 10, 1980, told Tracy that Patricia showed only slight brain damage, had autistic behavior and should have a new evaluation at the pediatric psychology department this spring. He has placed Patricia on two milligrams of valium a day to control her hyperventilating tendencies and hyperactivity in general behavior. It is hoped this treatment will allow her to attend more to teachers and parents as they try to direct her in learning situations. At this time the results of the EEG-Barre tests are not as yet available to Tracy and Kevin.

This will obviously have an impact on all those concerned in determining the least restrictive environment placement for Patricia and will be followed closely by project staff.

Facing the Reality of the Child's Handicap

This is the other side of the placement issue. Tracy and Kevin's high hopes for Patricia may or may not be justified, and may or may not be borne out in her future development. The latest encouragement has come to them in relation to the recent EEG results and doctors diagnosis of Patricia's "mild brain damage." What a new psychometric testing will reveal, of course, remains to be seen. Patricia's current classroom teachers and speech therapist are encouraged by the gains she has made since her return to school in February. But they are using caution in their predictions until all current and future test results are in and an EPPC can be conducted to determine the appropriate placement for Patricia for the 1980-1981 school year.

In the November 1979 interview, Kevin said very emphatically:

> "I'm sure Patricia is going to talk someday. She doesn't belong in an institution, she belongs here at home. She can do a lot for herself and let us know what she wants. I mean it when I say she'll talk someday."

Parental Awareness of Rights and Options Under the Law

It has become clearer to project staff after several interviews, home visits and phone contacts with Tracy and Kevin that they are not aware of their rights and options under the law. To be more specific, they know the law exists, but do not know the extent to which it is designed to provide an appropriate education for Patricia and rights of both child and parents.

Kevin has asked us, "What are my rights?" Tracy had said, "You see, the school she is in is not for the hearing impaired.", but she has not pursued that idea with any of the professionals involved with Patricia, or asked for a change during an EPPC meeting.

Tracy and Kevin had a misunderstanding with the school staff during January 1980, which got out of hand (emotionally) overnight. They called project staff asking for advice and assistance. Tracy was so upset she was going to pull Patricia out of school immediately. Their relationship with school staff had been a good one, and the researcher involved with the family agreed to serve as temporary liaison between Tracy and the school staff. Three phone calls were made and the researcher accompanied the family to the school. A calm discussion ensued, and the problem was resolved by discussing some options open to school personnel and the family. The researcher was thanked by both parties for being willing to play the role of calming advocate for all involved--school staff, the parents, and Patricia.

Project staff feel that Tracy has shared a great deal with us concerning her life as a teen parent and with two divorces and the many unhappy circumstances surrounding her before her marriage to Kevin. Tracy has felt put down by professionals on many occasions, and has had no defense against their spoken, or implied, accusations of her not being a "good parent." Her account of an encounter in 1977 depicts what can happen when a parent is totally unaware of existing laws or rights.

> "I went and saw the (local school district's) preschool and saw she (Patricia) would not benefit any more by changing her. They sort of hassled me about it because they were listening to what the speech clinic person was saying. She (local school district special education director) worshipped the ground that clinic person walked on. I knew different, she cut me down all the time.
>
> When I went to transfer Patricia she wasn't going to transfer the papers. She was making me feel like a child abuser. She said she (Patricia) needs more than the mainstreamed private preschool, she was angry. I said I know, it will do until I find a place I want her in. I don't want her here. I told you and told you that you're teaching her stuff she already knows and I want her learning how to express herself and let me know something. I know when my child is ready for something--I'll get records if I have to steal them.
>
> When we had the EPPC I didn't want her there, but she was. Nobody will ever listen to me."

Economic Costs

Patricia has had a lot of expensive medical treatment and educational intervention. Up to the present, medical insurance and subsidized programs as well as the intervention of the school district have sufficed to cover major evaluation and service costs for Patricia, and private efforts of a local chapter of a society for crippled children have provided additional funds for an expensive hearing aid. The parents have not had major economic burdens for Patricia. Our future data collection for this case will include closer inspection of cost issues for this case, since the family would be placed under severe economic strain if they had to cover any significant costs for Patricia's treatment.

3. Analysis of the Findings

Both major provisions of P.L. 94-142 chosen for in-depth analysis--least restrictive appropriate environment (LRAE) and parent involvement--illustrate how historical experience, socialization or training, and deep-seated attitudes have influenced the implementation of this law. Differences of opinion between parents and professionals in our cases were often made more difficult to resolve by (1) the strength of conviction behind the differences, and (2) consciousness of roles vis-à-vis each other. Eventual placement decisions among a number of our cases reflect the results of considerable negotiation between parents and professionals, often continuing over a period of years, and inevitably affecting the continuity of educational experience for the children themselves.

In three of the six cases presented in this report, relatively small local districts were either unable or unwilling to provide an appropriate placement alternative. In all three cases--Corwin, Gilbert, and Marshall--only the fact that the children live in a county rich with services prevented these children from being clearly inappropriately served. All three children have had to be transported to other districts in their county. In a related vein, three of our case children have had moderate to extensive experience in a self-contained special education institution--Helen Farrell in the county physically or otherwise health impaired (POHI) facility, Sean Gilbert and Patricia Oliver in the county center for trainable and severely mentally impaired (TMI/SMI) children and youth. The extent to which these settings comply with the LRAE provision of P.L. 94-142 is a complex and problematic issue.

Four of the children in the cases presented are multiply handicapped. The difficulty for parents and professionals in determining which disability to address primarily, how to design a program as close to "normal" as possible, and under what labels to place the child for service-eligibility purposes, is especially acute for children with complex diagnoses. Even for our two case children with clearcut diagnoses, the social correlates of being handicapped (e.g., feelings invoked in non-handicapped peers and teachers) have complicated the question of most appropriate environment.

Least Restrictive Appropriate Environment

This provision of P.L. 94-142 has proven difficult to implement both because of differences in interpreting the meaning and intent of the provision, and because in many of our cases alternative placements represented trade-offs, enhancing certain aspects of the children's development at the expense of others. In this section of the analysis a number of the issues that emerged from our cases relating to LRAE will be discussed.

In three of our cases--Corwin, Gilbert, and Marshall--relatively small local school districts have not been able to provide appropriate placement options for the children. In spite of district staff promises that they

were developing programs to meet the needs of these children, in all three cases these programs have not to the present been adequately developed. Thus, available alternatives have set the range for placements considered locally in seeking LRAE. In all three cases the children have had to participate in programs in neighboring districts, or in county-wide facilities such as the TMI/SMI center. The children and their families have had to adapt to what exists, seemingly in contradiction of the intent of P.L. 94-142.

In Larry Corwin's case, not only were he and his parents forced to seek placement in the special education program of a neighboring district, but he was placed in an EMI classroom, in spite of the fact that his primary eligibility category was EI. It happened that this setting was an excellent one. Nonetheless, this placement led to a county and state investigation of his home district, with the finding that it was the district's responsibility to provide an adequate setting for Larry, and until the district developed one, or received a "deviation" permit from the state, it was clearly out of compliance. The result of this finding was that Larry's home district quickly developed an ad hoc program for him in his home elementary school. More importantly, there was such resentment of the Corwins' efforts to assure an appropriate program for Larry that the year in his home school quickly became intolerable for him and his family, and he returned to the EMI classroom.

In Sean Gilbert's case, there has been no conflict to the present over his placement in the county TMI/SMI center. Nonetheless, this fall (September 1980) he has had an EPPC leading to a change in placement out of the TMI/SMI center, into a regular school setting. As his home district still has not developed an EMI program and other services to meet his needs, Sean must continue to travel to a neighboring school district to be educated. One difference between Sean's case and Larry Corwin's is that his parents have not felt the need to insist that their local district develop a program to meet his needs. In part this acceptance is due to their personalities, in part it is because they live in a county with a lot of services. They have accepted EPPC decisions and advice without questioning whether the intent of P.L. 94-142 was being met.

In Barry Marshall's case, lack of appropriate local district alternatives has been only part of a much larger conflict over the meaning of LRAE for Barry. Nonetheless, his home district clearly interpreted the LRAE requirement regarding provision of a continuum of services to mean helping Barry find an appropriate placement somewhere in the county, not providing it themselves. When the Marshalls thus determined that a private, integrated preschool was the most appropriate among the alternatives discussed at some of the early EPPCs, conflict arose over who would pay the costs of transportation. The Marshalls felt that if the district was not going to provide an appropriate program for Barry itself, it relinquished to some extent its right to "dictate" placement to them. They argued, in effect, if you're going to force us to look around the county for a placement for Barry, at least be gracious enough to pick up some of the undue (transportation) costs that would be entailed.

The effects on our study children of district inability or unwillingness to provide or develop appropriate programs for them have not been especially harmful to the children; there have been, though, clear negative effects on professional-parent relationships. Because the children live in a county with a wide array of services, their parents have always been able to find an adequate program for them, although sometimes based on travel over long distances. The very abundance of services has in fact been the cause of the long delay in developing special education programs in certain districts--neighboring districts had those programs already.

More importantly, the problem of small districts providing a range of services to a small number of children with a variety of handicapping conditions should not fall on the shoulders of the children themselves and their families. A number of the districts are involved in collaborative arrangements, pooling resources and each providing some piece of a total special education program with related services. These arrangements are by-and-large beneficial, but they have one drawback. They are a disincentive to districts doing all that is possible to see that a particular handicapped child gets at least a chance to be educated in his or her home district. Staff become somewhat too ready to suggest alternatives far from home, without at least struggling to find a way to educate the child close-by.

In a number of cases, difficulty in determining the cause and nature of the primary disability affecting our study children has made determination of LRAE difficult. Four study children are multiply handicapped, and three of those four have had dual or triple eligibility classifications. An extreme illustration of why difficulty in determining primary disability can be a problem is provided in the cases of Larry Corwin and Barry Marshall. Both these children have at times in their history been labelled simultaneously as EMI and LD--educable mentally impaired and learning disabled. These are contradictory classifications and, by definition, it would be extremely difficult to be both at the same time. Larry, along with his other classifications, has been labelled EI--emotionally impaired. Barry, likewise, has been labelled speech impaired and orthopedically impaired.

An appropriate program for a child with a specific learning disability is usually quite different than one for an EMI child. For Larry, being EMI and EI has been resolved by providing a program with time in both classrooms (as well as speech). Barry Marshall's case has been difficult to resolve. It is clear that, depending on how one looks at his needs, the kind of program developed for him would be extremely different. In his EPPCs the placement and program options discussed for Barry have often differed in kind as well as degree. For example, at his fourth EPPC, options discussed included a mainstreamed preschool classroom, a self-contained classroom for learning disabled children, and the local district's orthopedic room. (Most professionals and his parents have agreed on his need for extensive speech therapy.) At a later EPPC, his sixth, the principal of Barry's home school suggested the newly opened EMI room in his home school.

The question implicitly or explicitly addressed in program planning for the multiply handicapped children in our study has generally been: what are the behavioral and educational impediments to optimal functioning that we want to attack? Basing planning on this question has helped educators and parents sort out the complicated needs of children like Patricia Oliver. This child's handicaps include hearing impairment, speech impairment, orthopedic impairment, fairly severe mental impairment, and moderate visual impairment. Two physicians testing her last year (1979-80 school year) even suggested the possibility of autism. To the present, the rule for providing a program for Patricia has been optimum treatment for her greatest deficit. Until recently, this meant a program focused on her needs as trainable/mentally impaired and speech impaired. This fall (1980), as a result of renewed testing, Patricia's teachers feel that the key to unlocking her intellectual potential (still unclear) is to focus on her hearing and speech impairments.

The specialized and fractional nature of special education services has made provision of an appropriate program and environment for the multiply handicapped children in our study more difficult. Larry Corwin, for example, would benefit from an integrated EMI/EI classroom, where a broader range of his needs would be addressed in a coordinated manner. As it is, his EMI and EI teachers take a different approach to him, work with different educational materials, and have different classroom environments. Patricia Oliver would benefit from an integrated hearing impaired TMI classroom, at least transitionally. Barry Marshall would certainly benefit from a program organized to meet, and focused on, a broader range of his needs.

Three factors impede the provision of more fully coordinated programs for our study children. First, the classification system mandated under P.L. 94-142 tends to lead EPPC and IEP committees to choose among alternative environments focusing on different kinds of needs. Second, most special education teachers are trained to focus on one, or at most two, handicapping conditions. Third, lack of resources prevents school districts from providing "combined" programs in the continuum of services offered. Dual or triple classification is discouraged in the districts in which we have worked, usually for good reason--the various pieces of the total special education program are quite different from each other. Nonetheless, as the cases of our study children illustrate, multiply involved children require those dual or triple classifications to assure multiple needs are met. The pieces tend to be tacked on to each other, though, rather than thoughtfully fit together.

A similar impediment to provision of LRAE for our study children has been lack of an institutional continuum in placements. In terms of institutional settings, our study children and their parents have been faced, quite frequently, with rather stark choices. Orthopedically involved children, for example Helen Farrell, have been

faced with a choice between the county POHI center, where they would have no contact with non-handicapped peers, and a regular classroom, where they would have limited or no contact with other orthopedically involved children and POHI trained teachers. Mentally impaired children in our study have been faced with the choice between the self-contained isolation of the TMI/SMI center and an EMI classroom in a regular school. There is no TMI/SMI setting in the regular schools; thus, parents have reluctantly chosen the isolation to have access to the TMI/SMI services.

There is thus something of a quantum leap in institutional settings from largely mainstreamed to totally isolated. In classification terms that leap is from moderate to severe impairment. The need for settings bridging that gap has begun to be addressed in the county; for example, a new POHI facility is being built, attached to a regular elementary school and close by middle and high schools. To the present, the county POHI center has been ruled administratively as something of a separate fiefdom. It is hoped that this institutional integration will lead to greater administrative coordination between special education and regular education.

The lack of a continuum in institutional settings makes provision of LRAE to children who fall in the gray area, between degree of involvement categories, more difficult. There has been a certain schizophrenia evident in the programs of those of our study children who don't fit easily into categories of moderately impaired or severely impaired. The frequent reliance on and push for "shared time programs," most clearly seen in the cases of Helen Farrell, Barry Marshall, and Joseph Edwards, and to a lesser extent in Larry Corwin's, reflect lack of consensus on degree of impairment and the effect of that impairment on each child's total functioning. When part of a child's program reflects a belief that he or she can function adequately with non-handicapped peers, and part totally isolates a child from those peers, placing him or her just with handicapped peers, then that child does not have a truly coherent educational environment. An alternative school and classroom setting appropriate to the whole child--strengths and needs--would be less restrictive for at least a few of our study children.

The seemingly complex programs in which a number of our study children find themselves--shuffling from regular classroom, to EMI room, to speech, to EI room, back to EMI room, etc.--provide an indication that the schools in this part of Michigan are struggling to provide programs that meet the full range of handicapped children's needs. What is happening is that pieces of the special education system and the regular education system are being grafted onto each other, with the mandates of P.L. 94-142 being the glue that binds them together. The most appropriate environment for most of our study children is in an educational world somewhere between the two systems, and that world is still in the making.

At the extremes of the two systems are the totally self-contained special education facility--such as the county TMI/SMI and POHI centers--and the regular classroom in which the special needs child is sometimes placed full-time. Under what conditions do these settings satisfy the letter and intent of the LRAE provision of P.L. 94-142? Patricia Oliver and Sean Gilbert have had almost no contact with non-handicapped peers during their tenure at the county TMI/SMI center. Yet, observing them, one doesn't feel they are in a restrictive environment. That setting has seemed appropriate in itself; it is when one thinks of the social world outside the facility that the restrictiveness of it is apparent. Yet the staff at the center are warm and caring; they make whatever attempts they can to bring the outside world in, and take the children to the outside world; and they see their goal, in many cases, as moving children toward normalization. For example, Sean Gilbert moved this fall out of the TMI/SMI center into a regular school setting.

Joseph Edwards' experience in the regular kindergarten, with only speech therapy services, suggests that even for moderately to severely involved children--Joseph has Down's Syndrome--full-time in a regular classroom can be appropriate. Yet the experiences of Helen Farrell and her parents, and Larry Corwin and his parents illustrate that both those extremes in setting can just as easily be restrictive and inappropriate environments. As will be recalled, once the county POHI center "captured" Helen, they wanted her full program to be there, even when there was clear evidence that she thrived in a mainstreamed setting. It is the policy of the POHI center administration not to encourage orthopedically involved children to participate whenever they can in the regular schools' programs. In Larry Corwin's case, both his teachers and his parents have discovered that, because of his special emotional and cognitive needs, a regular classroom environment is frequently a very restrictive place for him. In fact, the teacher who knows him best feels that he is moving away from normalization.

Thus, the physical setting can make it more, or less, difficult to achieve the least restrictive and still appropriate environment for a handicapped child. Yet the above evidence from our cases illustrates that it is the behavior and attitudes of the staff and the specific needs of the child that have the most significant influence on achievement of LRAE. When Sean Gilbert's teachers at the TMI/SMI center said that in no way did they consider his placement there as permanent, that attitude itself helped propel him toward normalization, and a regular school environment. When Joseph Edwards' regular kindergarten teacher said, in the face of consensus among the other professionals at Joseph's recent EPPC that he should be in a self-contained EMI classroom, "I haven't made up my mind yet what's best for him", she propelled him toward normalization. This year (1980-81), thus far, Joseph is successfully negotiating the transition to a regular first grade class.

While the educational systems serving our study children are slowly adjusting to the demands of educating them in the least restrictive appropriate environment, the children themselves, in a few cases, are on developmental paths moving them away from normalization. In the cases of Larry Corwin, Joseph Edwards, and Patricia Oliver, the developmental gap between them and their age-mates grows wider year-by-year. Larry has proven to be particularly sensitive to this trend, which is one reason why his teachers have recommended less time in a regular class each year as he has gotten older. Joseph's parents realize that he will have to be in first grade again next year, if he wants to continue in a regular class--he will then be two years older than his classmates. Eventually, he will be so much older than his classmates that more time in a self-contained EMI setting will be inevitable. Patricia Oliver remained in a mainstreamed preschool environment for a year and a half. At a certain point it became clear that she needed more individualized attention to her numerous specific disabilities than could be provided in that setting. This year (1980-81) she will probably move to the TMI/SMI center's hearing impaired classroom, to work on communication pre-requisites.

In the cases of Larry Corwin and Patricia Oliver, while moving away from normalization in terms of mainstreaming they are being moved into or toward environments that place the least restrictions on their performance by attacking specifically the impediments to optimal performance. That particular intent of the LRAE provision is being met in their cases. Joseph Edwards is theoretically in an environment which, as his father puts it, will allow him to "fail at the highest level". His parents argue that models for him and expectations of him will be higher in a regular classroom setting. His successful, but somewhat trying, experience in a regular kindergarten during the 1979-80 school year suggests that there are certain pre-requisites to a successful mainstreamed experience for handicapped children.

The most important pre-requisites are preparation time, and then ongoing support for the classroom teacher serving these children. Both psychological and technical preparation appear to be crucial. For example, Larry Corwin's regular classroom teacher viewed him and his presence in her class for small periods of time each day as a burden. His already great social isolation was reinforced by her lack of attention to him, and lack of effort to integrate him socially. The children used her as a model, and likewise made no effort to include him. In contrast, Joseph Edward's teacher, who suddenly found him assigned to her kindergarten class in December 1979, made a special effort to bring him in and make him part of the class. Her respect for him, her affection, and her patience when necessary, served as a model that most of the children picked up on immediately. She was

psychologically prepared to have him in her class, and did not unconsciously or passively resist his presence.

Neither Larry's nor Joseph's regular classroom teachers received adequate technical preparation for meeting the special needs of these children. This problem had more of an impact on Joseph's teacher, for she had him in her kindergarten class the whole afternoon. The strategies she developed for encouraging Joseph's academic progress were developed through trial and error, and with the support of Joseph's mother, who shared some materials on developmental needs and abilities of Down's Syndrome children with her. Equally as important, Joseph's teacher received little ongoing support for her work with him in the classroom; she was constrained by lack of time to work individually with Joseph. She had an aide most afternoons, but the aide felt somewhat uncomfortable with Joseph. Finally, she did not have materials that were designed to meet his educational needs.

A problem that many of our study children have faced, that has impeded achievement of LRAE for them, is the number of transitions from classroom to classroom, and in a few cases institution to institution, that has had to be made everyday. In Helen Farrell's case, until this year she had to move every day between two totally distinct institutional environments, with educational strategies, expectations of her, and physical surroundings very different from each other. Larry Corwin, during his days, moves from an EMI classroom, to an EI classroom, to speech, to his regular classroom, and sometimes back again to EMI or EI. In each setting expectations are different, the classroom atmosphere is different, the children may be different, goals for him and content are different. Larry finds it hard enough to make friends in one setting; yet he must strive to do so in three or four. Joseph Edwards' mother refused his teacher-consultant services last year (1979-80), to minimize transitions in his daily schedule (he was already leaving for speech). Barry Marshall's mother has noted that the cosmetic mainstreaming he gets for art, music, gym does a lot more harm than good for him. She feels that the constant "in-and-out" all day cannot be good for Barry and his EMI classmates: "they need the same, if not more, continuity in their lives as the normal kids." She feels more is being asked of the handicapped children than of the non-handicapped.

We have found in our study cases that the decision-making process leading to determination of least restrictive appropriate environment has a moderate influence on achievement of that environment. The position from which decision-making meetings begin often shapes the nature of discussion and final determinations. We have noted three points of departure in our cases: let's assume this child should be integrated into a regular classroom setting unless clear justification for a self-contained special education classroom is proven (Joseph Edwards); let's set a range of options and discuss each in turn

(Helen Farrell, May 1980 EPPC); mainstreaming is clearly inappropriate, let's look at other options (Barry Marshall). We have found that the middle option, though not inherently closest to the intent of the LRAE provision, seems to lead to the most constructive decision-making process. Parents, or professionals, are less likely to feel "railroaded" if each option is fully discussed. Advantages and disadvantages of any particular placement option are more likely to be brought out.

We have found, as might be expected, that when parents' and professionals' perspectives are given equal weight, decisions leading to achievement of LRAE are more likely to be made. An honest negotiation process, though it can still be emotion-laden and painful, contributes to construction of a balanced program. The May 1980 EPPC of Helen Farrell illustrates this finding. In none of our cases have professionals simply overwhelmed parents with their administrative and moral authority. Yet in the early years of the Corwin and Farrell cases, and on a continuing basis in the Marshall case, adversarial interactions at EPPC meetings have left parents shaken, angry, and confused. Strains in parent-professional relations have affected teacher attitudes toward two of our study children (Larry Corwin, Helen Farrell) at school, leading in the early years to a more restrictive environment (in atmosphere) for these children.

The decision-making process leading to LRAE often involves consideration of trade-offs in program focus among different aspects of a child's development. Although cognitive, socio-emotional, and physical development are in actuality closely intertwined, in a few of our cases choice of one or another placement has been seen to mean enhancement of development in one area, at the expense of another. Parents of our children have been less likely to think in terms of trade-off than professionals, but parents too are aware of the need to meet a number of kinds of needs in their children. The cases of Helen Farrell and Joseph Edwards provide the clearest illustration of this issue. Patricia Oliver's case, due to the great number of her remedial needs, also provides an illustration.

Helen Farrell's teachers at the POHI center have always felt that her full-time participation in the private, mainstreamed elementary school program might meet her social needs, but would not be the most beneficial placement to meet her academic and physical needs. Helen's parents disagree strongly with that assessment in the academic area, but have sensed that her program of physical therapy--crucial to her struggle for autonomous mobility--might be fuller at the POHI center. They are currently monitoring the amount of physical therapy she gets weekly in the mainstreamed setting. Joseph Edwards' teachers and evaluators have historically felt that his cognitive needs could best be met in a self-contained EMI classroom, although they have acknowledged that he profits socially from mainstreamed settings. They have thus viewed LRAE decisions as a trade-off between more effectively meeting

Joseph's cognitive needs, or more effectively meeting his social needs. Joseph's parents have not felt to the present that they are trading-off cognitive for social development in seeking regular classroom placement for him. But they feel this might become an issue in the near future.

Patricia Oliver has had so many needs during her early years that it has been difficult to meet them all simultaneously. Currently her hearing impairment is seen as potentially the central impediment to her development: it is preventing fuller interaction with the world. Yet, if she enters the TMI/SMI center's hearing impaired program this fall (1980), the focus on teaching her signing and related skills will be at the expense of time for specific activities enhancing her cognitive development. She desperately needs tools to communicate; yet she also needs a full program of cognitive stimulation. Placement will determine which receives more emphasis, although neither will be neglected.

Though the nature and degree of a child's handicapping condition have clearly influenced parental and professional desires with respect to choice of educational environment(s), other factors have also been influential. While it is possible to generalize that the more severe the handicapping condition the less likely will be placement in a regular classroom, parental preferences and number of suitable alternatives available also influence likelihood of mainstreaming, sometimes independently of nature or severity of handicapping condition. Joseph Edwards' case illustrates the former influence; Helen Farrell's the latter. With a few exceptions, professionals involved with particular children in our study generally have opted for a less mainstreamed educational program than those same children's parents. This generalization does not hold for our most severely involved child, Patricia Oliver.

The analysis of how the least restrictive appropriate environment provision of P.L. 94-142 has been implemented in our study cases reveals this to be a complex, often problematic provision of the law. Influences on determination of LRAE for any particular child are multiple: the size of his or her school district, district fiscal resources, service availability in the general area, administrative and programatic integration between special education and regular education, the strength of parental and professional feelings, the nature of the EPPC/IEP decision-making process, the age of the child, and of course the specific needs of the child, all interact in a process that often continues from year to year. By and large, those involved in this process feel they have the best interest of the child in mind, and at least attempt to understand opposing viewpoints.

In none of our cases did we find a simplistic drive toward mainstreaming, or in the opposite direction, on anyone's part. All discussion took place in the context of specific children's needs. Yet, powerful differences in opinion and perspective have persisted over the years in a few of our cases. Fundamental differences concerning the

best way to meet a child's needs--in Helen Farrell's case--have been proven difficult to resolve. We have found that as long as communication continues--among teachers and therapists, between professionals and parents, between administrators--many problems can be worked out, at least to the point of compromise. When communication fails, it is inevitably the child who suffers most.

Parent Involvement

P.L. 94-142 has redefined the rights and responsibilities of a select group of parents--those of handicapped children--in decision-making regarding all aspects of their children's educational programs. In many ways, the intended beneficiaries of P.L. 94-142 have been not just handicapped children, but their parents as well. The mandate to involve parents in program planning, decision-making, and evaluation has, obviously, changed not only their roles in the educational process; it has changed professionals' roles too. Professionals are now to be partners with parents in that process.

What has the impact of these changing rights, responsibilities, and roles been on our study children, their parents, and those serving the children? The changes mandated under P.L. 94-142 have required new administrative procedures. Perhaps more fundamentally, they have required changes in deeply rooted patterns of interaction and feelings about oneself as a decision-maker. Much has become exposed that was hidden. As one parent in our study recently noted: "It's impossible to describe the feeling, of being totally vulnerable, of having no control over the life of my child, when I enter an EPPC meeting." Attitudes and beliefs about one's status, long accepted, are suddenly turned upside down: this has been true for parents and professionals.

The findings regarding parent involvement in our case studies shed light on three central issues: the implications of genuine versus cosmetic parent involvement; the factors differentiating the way various parents use their rights under the law; and the implications of school systems taking either a pro-active or reactive stance in informing parents of their rights and responsibilities. Threaded through these, and a number of corollary issues to be discussed, has been the often difficult process of adjusting relationships, expectations, and behavior.

The range of involvement in program planning, decision-making, and evaluation among our study parents has varied more in nature than in degree. All our study parents--usually, the mothers of our study children--have taken advantage of the opportunity to participate in planning and decision-making meetings; most have participated at some time in IEP formulation (a narrower task in Michigan); and most have sought and received evaluation findings, written plans, and related documents. The basic difference among our study parents has been in the role they have carved out for themselves, or that they have been encouraged to take. Patricia Oliver's mother and step-father, with a limited awareness of their rights, and having a lot of needs themselves, have tended

to rely on professionals to define Patricia's program. The Gilberts, with a general awareness of their rights, but having no strong objections to Sean's placement, have tended to go along with professional's preferences; they, though, have known what they wanted for Sean. The Corwins, Edwards, Farrells and Marhsalls have, to various degrees, taken an active role in the program development process, generally learning their rights as they've gone along, gaining an increasing sense of themselves as decision-makers. These parents, in asserting themselves, have brought out all kinds of underlying feelings in professionals, the presence of which charges the atmosphere of planning and decision-making meetings.

Two kinds of factors have differentiated the way our study parents have used their rights under P.L. 94-142: institutional/environmental factors, external to the particulars of the situation; and situational factors such as the status, backgrounds and personalities of the participants, the history of a particular family's relationship with the schools, and the nature of a particular child's needs. As will be seen, the institutional/environmental factors often merge with situational factors as a case develops.

The institutional factors are illustrated most clearly in the Corwin, Farrell, and Marshall cases. Larry Corwin's parents were forced into an activist role when it became clear to them that their home school district was not going to provide an appropriate program for him. The fact that it was a small district, and that there were no options for them within the district once his home elementary school principal indicated that the school simply didn't have the resources to meet Larry's needs ("we have other children to think of too") backed the Corwins against a wall. Because it was a small school district, their activism quickly became well known to administrators, teachers, and other professionals, with the result that the whole family was branded as "trouble." (Larry's older brother had trouble acquiring badly needed remedial reading services, until Mrs. Corwin threatened to begin due process proceedings to acquire those services for him.) The supportiveness of the neighboring district's staff, and their attitudes of "don't worry, we'll work any problems out," was a powerful relief for Larry's parents. They have now retreated considerably from their activism of earlier years because they trust that any decisions made will be in Larry's best interest.

The difficulty small districts can have in providing adequate services to a child, with the result of activating parents' concerns, can be seen also in Barry Marshall's case. The Marshalls have never felt that Barry has been getting adequate speech therapy and communication skills work. The district has responded that he is getting "all that is available and all that he needs." The Marshalls more generally have had a long history of negotiating with their home school district to get what they see as adequate (more) services for him. Judy Marshall wonders if the district decision to mainstream him last year (1979-80)

was really in his best interest; whether it might not have been a way of providing him less services. The fact that the district has all the special education programs in one building she feels is also more for the district's benefit than for the children's. The Marshall's activism over the years has not resulted in their minds in adequate services for Barry. That is one of the reasons they decided recently to move to another county that had group homes for handicapped children, and where they felt Barry could have his needs met.

Helen Farrell's parents, particularly her mother, have also become very involved in formulation of her educational program for reasons attributable to the institutions serving Helen. The POHI center's philosophy and values, described in her case study, have been impediments to Helen receiving an appropriate education in the least restrictive environment, in her parent's minds. The institution's philosophy, that most POHI children are better served if they take their full program there, contradicted the concrete evidence that Helen thrived in a mainstreamed environment. This conflict led to years of struggle over Helen's placement, with extremely high emotional costs for Helen and her parents.

In each of the three cases reviewed above, the parents were drawn into an activist role by what they saw as failures in the institutional system serving their children. In the Corwin and Marshall cases it was lack of adequate resources, compounded by professionals' resentment of demands made by the parents, that led to parental activism; in the Farrell case it was the philosophy of the institution that led to conflict. While it doesn't automatically follow that satisfaction with institutional resources made available and institutional philosophy leads to less active parent involvement--as discussion of the Edwards case will demonstrate--in general this holds true. At least part of the reason for the Gilberts' and Lamberts' (Patricia Oliver) less active involvement was satisfaction with services.

In all our cases situational factors clearly influenced parent involvement, although not in a simple way. Different factors have played a role in each case, and it is hard to find particular factors that consistently differentiate degree and nature of parent involvement. Two factors that we might have expected to clearly have an influence on parent involvement--social status of the family, and parental knowledge of the provisions and intent of P.L. 94-142--did not prove to be seminal in differentiating involvement among our families. While none of the parents included in this report have a high social status in their communities, only one set, the Lamberts, has been hesitant to assert itself in the face of professional authority. In a related vein, almost all of our families started out with an extremely limited knowledge of P.L. 94-142; but this didn't necessarily impede their activism to get their children's needs met.

Personal/situational factors that did influence parent involvement include: the social situation of the family, personality of the parents, history of relations with the schools, attitudes of professionals, the degree of complexity of the child's needs, clarity of diagnosis of the child's handicapping condition, parental feelings concerning adequacy of services being offered, and parental expectations of their child. The Edwards case illustrates a number of these factors. The Edwards (particularly Mary) are what can be described as very assertive and determined parents. They demonstrated this before Joseph was a year old, in turning down the day training center program of their county's Mental Retardation Service Center, expressing the feeling that Joseph was functioning at a higher level than the other children at the center. Although P.L. 94-142 hadn't been passed at the time, and they knew little of Michigan's law, the Edwards report that they were clearly aware of their rights as parents.

The Edwards have always had high expectations of Joseph, not letting his status as a Down's Syndrome child determine expectations of him. They have actively pushed over the years to have Joseph in environments that would not prevent him from achieving his potential. Thus, in spite of the fact that Joseph has always had excellent services available to him, professionals involved with the Edwards have often felt pushed or pressured--Mary Edwards was always looking over their shoulders to make sure Joseph was "getting the best."

Patricia Oliver's case illustrates some of the other factors cited above. The complexity of her needs has left her parents somewhat overwhelmed, and willing to turn the job of meeting those needs over to the school and medical systems. On the other hand, Patricia's parents have wanted their input taken seriously at decision-making meetings, and have wanted Patricia's problems explained to them in understandable terms. Patricia's mother has noted feelings of inadequacy and helplessness at meetings, and a sense that she was being blamed for some of Patricia's problems. Nonetheless, school staff have made considerable efforts to understand the Lamberts' needs and concerns. The Lamberts are very young parents, with two other children to take care of and no financial security; their generally stressful situation has prevented them from being as involved in Patricia's case as they would have liked to be.

Helen Farrell's case provides probably the clearest illustration of the influence professionals' attitudes can have on parent involvement. The dependency and vulnerability parents of handicapped children experience in the face of professional authority has been widely noted. The potential for abuse is great, and luckily the great majority of professionals have strived hard to accommodate the new roles for parents in decision-making processes. Helen Farrell's case illustrates how easily professional attitudes regarding parent involvement can be devastating to parents and child. Helen's parents and the POHI school staff knew that Helen absolutely needed their physical therapy services,

and the POHI staff hung this like a sword over EPPC meetings for years. They also all but told the Farrells that they, the POHI specialists, were in the best position to determine Helen's program needs--they were trained to know those needs. Their inflexibility prevented them from hearing the abundant evidence presented indicating that Helen thrived in an integrated school environment. Their occasionally active hostility to the Farrells caused the latter great pain; so did the need to compromise Helen's academic program for the sake of assuring adequate physical therapy. The Farrells, who wanted to work with professionals to meet Helen's needs, were forced into an adversarial role vis-a-vis professionals.

The Marshall's too have found themselves in a somewhat adversarial role vis-a-vis school officials, but for a different reason: lack of clarity regarding the nature of Barry's handicaps and the most effective means to alleviate them. The Marshalls have become increasingly frustrated with the seeming inability of the schools to provide a successful program for Barry. This has translated, at least in part, into a feeling that the schools haven't consulted them adequately in seeking the best program for Barry. When they have felt satisfied with Barry's program, as they did for a while in the mid-1970s, school officials have proceeded to pull the rug out from under them by requesting a review and suggesting a new program. While some of the Marshalls' frustration with the schools has been legitimate, some of it is displaced frustration over the years of unsuccessful struggle to give Barry the tools to communicate with his world.

The parent involvement provision of P.L. 94-142 mandated a number of administrative mechanisms to ensure parent involvement in their children's programs. These include adequate prior notification of meetings regarding their child's program (planning, decision-making, review), notification before any planned changes in daily or weekly program, access to all records kept on their child, and efforts to time meetings so parents can attend. Even more basic, parents are to be informed of all the above and related rights for them and their children under P.L. 94-142. We have noted a number of trends in development of these mechanisms in our cases. The trends generally relate to school efforts to satisfy the intent as well as the letter of the law.

We have found that the schools generally do not take an active role in informing parents of their and their children's rights, although school staff willingly provide information when asked. Most of our study parents picked up information on P.L. 94-142 from other parents of handicapped children, in parent-support groups, or from advocates. None of our parents are fully aware of all the provisions of P.L. 94-142; some have full knowledge of selected provisions, some have a general sense of the requirements and intent of the law. In general, our study parents have acquired information on particular provisions on a "need-to-know" basis: our least active parents probably have least knowledge of their rights under the law. (It is hard to know which

is cause and which is effect here, although we have found the "need-to-know" incentive a strong one.) In the area of informing parents about the law, the schools have generally met the letter rather than the spirit of the law.

In very few cases have the prior notification or access to records requirements not been met. In almost all our cases, efforts have been made to arrange meetings so that at least one parent could attend. When necessary, parents have been consulted by phone. The intent as well as the letter of the law was clearly met in this area. With respect to records a more complicated picture emerges. Probably only the Edwards have full copies of everything in Joseph's school records, although most of our families have some of the documents in their children's files. Schools clearly take a reactive position in this area, probably fearing the time and cost involved in voluntarily providing records to parents.[1] In a few of our cases, parents have not been aware that school systems often have two files on handicapped children--a regular file and a special education file. Thus, they have sought information from what they thought was the only file. Also, not being given a list of what was in the files, some of our parents have not known what to ask for.

Generally, our study parents have been informed of evaluations and received reports of evaluation findings. In a few instances--most notably once in Joseph Edwards' case, and once in Helen Farrell's--evaluations were conducted without the parents' knowledge or consent. Rarely are evaluation findings translated into non-technical language, and this has frustrated parents in almost all our cases. Parents of mentally impaired children in our study find numerical scores of I.Q., D.Q. (developmental quotient), or abilities particularly frustrating. Mary Edwards spoke for a number of the parents when she noted a tendency for most evaluation reports to focus on what Joseph can't do, rather than what he can do (the exception being developmental profiles).

Perhaps the clearest single indicator of the impact of the parent involvement provision of P.L. 94-142 on our study families has been the nature of the process of EPPC, IEP, and IEP review meetings. The EPPC meeting by its very nature is extremely stressful for parents. As Helen Farrell's mother has noted "a group of professionals are sitting around a table discussing the future of your child." The professionals' control over that child's future, their authority and status, and their numbers--one parent is usually surrounded by five or six professionals--make it difficult for parents to assert their perspectives.

One of two patterns of interaction was evident at most EPPC meetings. In the first the parent is an integral part of the discussion, periodically commenting on the issue of the moment. In the other, the professionals present and discuss material, with the parents remaining largely silent; then, at some point, an advocate or one of the professionals asks: "What do you think, Mrs. and Mr. _____?" The reasons for the presence of one or the other of these two patterns

[1]It is important to note that under the Act schools must inform parents of their rights to see their child's records, but are not required to furnish them unless asked. Thus a reactive position meets the intent of the Act.

can be found in the structure of the process outlined by the EPPC chair, in the professionals' level of awareness of how the parents might be feeling, and in the parents' own sense of their role at the meeting.

The general stages of almost all EPPC meetings, except for those involving grievances, problems in program delivery, and related special matters, are: presentation of evaluation and progress reports, laying out of program options for the future, discussion of the options, and choice of one of the options. At some meetings a child's eligibility for special education services under one or another category will be discussed, approved, or re-confirmed. This general meeting structure tended in all our cases to leave parents silent for the first half of the EPPC meeting; therefore, the first interaction pattern described above has predominated at most EPPCs. The exception occurs when parents are invited to share their perspective on a child's progress, or when the parents insert themselves into the presentation. Sean Gilbert's most recent EPPC illustrates the former: at that meeting his mother was asked to and in fact showed her perceptions of the gains he had made at the county TMI/SMI center, and the nature of his behavior at home. The latter exception--parents inserting themselves into the presentation--has occurred in at least a few of Joseph Edwards' EPPCs.

The Edwards in fact have developed a number of strategies to assure that they are given an active role to play at EPPCs. They prepare for these meetings extremely thoroughly, including thinking through what they want for Joseph, how to negotiate, and the reasons for their position. Professionals are aware of their preparation. They have had independent evaluations done which they had a role in presenting. They let meeting participants know that they, the parents, expect to have an active role. They generally bring on advocate to add some balance to the "parents' side" at the table. And they are persistent. They have generally been very successful in getting the placement they desired for Joseph.

We have found that when parents are asked concrete, specific questions, and share concrete information integral to decision-making, then they are truly involved in decision-making. Also, when it is apparent that the professionals at the table are actually listening to and considering what the parents are saying, and are not just being polite, then the parents are truly involved in decision-making. When the school psychologist at Joseph Edwards' most recent EPPC asked the Edwards' not to just note what they wanted but to explain why they thought he should be in a regular first grade class, the Edwards made a fundamental contribution to that meeting. Unfortunately, parents are too fearful and professionals too unsure of how to bring parents in to the discussion, in most cases. Thus, integral involvement of parents in planning, decision-making and review meetings is one impact of P.L. 94-142 yet to be fully felt.

The most problematic situation at EPPCs is when all or most of the professionals agree on one placement or program, and the parents want another. This situation has not been infrequent in our cases, expecially

Joseph Edwards', Helen Farrell's and Barry Marhsall's. The Edwards have usually got what they wanted. The Farrells have had to compromise (until this last year's EPPC, when preparation, the presence of two advocates, and the presence of this study's staff taping the meeting, led to the Farrell's getting what they wanted). The Marshalls have generally not got what they wanted; they have had to resort to due process mechanisms. Why disagreements sometimes lead to compromise sometimes to parents having their way, and sometimes to due process proceedings is hard to say. We have noted that the Edwards have always known what they wanted and been well prepared. In addition, professionals have always been accommodating with them. In the Farrells' case we suspect that the mutual awareness of how strong feelings were on each side led to compromise; the situation was only just in hand. Also, the evidence that Helen could function well in an integrated setting was always there. The Marshalls resorted to due process, we suspect, out of sheer frustration with the schools' inability to help Barry progress; it was the only means of protest they were aware of.

All of our study parents are significantly more involved in planning for and deciding about the educational program of their handicapped children than they would have been if their rights were not defined in law. Because the changes in relationships mandated and implied in P.L. 94-142 are fundamental, it is easy to understand why both parents and professionals are still struggling to come to terms with those changes in late 1980. The important point emerging from the evidence in our cases is that, except in rare instances, they <u>are</u> struggling. As parents have become more involved, too, this involvement has both enhanced their sense of self as decision-maker, and led to more effective programs for their children.

Conclusions

In examining the impact of P.L. 94-142 on nine handicapped children and their families living in one county in Michigan, we have by no means provided a vehicle for surveying the effects of that law on the general population of handicapped individuals. Rather, we have provided a vehicle for a small number of families and those serving them to share their experiences in coming to understand their rights and responsibilities under the law, and then attempting to translate that understanding into new patterns of behavior and interaction. The strength of our study has been in the depth to which we have had the opportunity to go, thanks to the openness and sense of responsibility of both parents and professionals.

We have come to agree with Edwin Martin, after working with our case families for two years, that P.L. 94-142 is indeed the most important legislation for the handicapped ever passed. We have observed firsthand the human impact of that legislation. Painful adjustments have had to be made. Rights spelled out in the law have still had to

be fought for, in some cases. Resources have had to be found by school districts to meet new responsibilities. Teachers have had to find ears to listen to parents, and parents words to express their ideas and feelings. Handicapped children have found themselves, in at least some cases, more clearly in the mainstream of educational and social life.

EXECUTIVE SUMMARY

STUDY OF THE IMPACT OF P.L. 94-142 ON THE HANDICAPPED CHILD AND FAMILY: INSTITUTIONAL RESPONSES AND THEIR CONSEQUENCES

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Executive Summary

Overview

This report presents selected findings of a two year study that was designed to examine the impact of P.L. 94-142, The Education For All Handicapped Children Act, on handicapped children and their families. Since much of this impact is mediated by the way institutions serving handicapped children have responded to the mandates of P.L. 94-142, the study was subtitled "Institutional Responses and their Consequences." The study was itself part of a larger effort that the Office of Special Education (then Bureau of Education for the Handicapped) was engaged in to analyze the administrative, fiscal, and human consequences of implementing P.L. 94-142; and also to examine the extent to which the intent of the Act is being met.

Our sample consisted of nine handicapped children aged 5 to 10 and their families, living in one county in southeast Michigan. We followed the children in-depth as they negotiated the world of schools, hospitals, clinics, and other institutions serving handicapped children in various ways. The children represented a wide range in nature and severity of handicapping conditions; had varying educational and related service needs; and came from very diverse communities in size, wealth, and resource availability. In our study we interviewed parents, teachers, therapists, physicians, school administrators, the children's evaluation teams, and others. We observed the children in their school settings. We analyzed records, evaluation documents, reports, IEPs as written, and other relevant documents. And we attended meetings where decision-making about educational placement and program planning took place. Through this multifaceted data collection we tried to understand responses to the major provisions of P.L. 94-142 through the eyes of those affected in various ways.

The full report from which this summary is abstracted contains in-depth case studies of six of our nine study families, and examines implementation of five of the major requirements of P.L. 94-142: protection in evaluation procedures, procedural due process, individualized educational programs, least restrictive appropriate environment, and parent involvement.[1] The report also contained separate analysis and synthesis of the findings from our cases in the areas of least restrictive appropriate environment and parent involvement. We chose these for special analysis because they are two particularly complex and crucial provisions of the Act, and because our findings in these areas were particularly striking. It is this analysis, along with our most important general findings, that is presented in the current summary.

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[1]The interested reader will be able to secure the full report through the ERIC system in late winter 1981, or can write to the authors to receive a copy at cost. The report is 125 pages.

The Education For All Handicapped Children Act: In Brief

The Education For All Handicapped Children Act of 1975, P.L. 94-142, has been described by Edwin Martin, Assistant Secretary for Special Education and Rehabilitative Services, as the most important legislation for the handicapped ever passed. Its central provisions, in their interpretation and implementation, are beginning to have a significant impact on the nature of education for handicapped children and youth. These provisions include: (1) the right of all handicapped children aged 3 to 21 to a free appropriate public/education[1]; (2) protection for handicapped children in evaluation procedures--the right to non-discriminatory, fair, comprehensive evaluation for purposes of classification and program development; (3) due process safeguards for handicapped children and their families including prior notice of meetings, plans, or changes in a child's program, access to a child's records, a time frame for the whole special education process, and procedures for protesting decisions; (4) the right for parents and others to participate in decision-making processes; (5) least restrictive appropriate placement--the right of every handicapped child to be educated, to the extent appropriate, with non-handicapped peers; and (6) the right of every handicapped child to have an individualized educational program. These provisions shape a mandatory process of planning, decision-making, program design, implementation, and review. P.L. 94-142 also authorizes funds to contribute to the local cost of implementing the above and related provisions.

A Note on Michigan's Special Education Law

Michigan has had its own special education law, P.A. 198, since 1973. This law was designed to be implemented immediately, and by 1976 most local education agencies in Michigan were making serious attempts at compliance. P.L. 94-142 and P.A. 198 are quite parallel in their intent and most of their provisions. However, Michigan's law differed from the federal law during the years of our study in two notable respects (one of these differences has since been addressed). First, the state law mandates services for handicapped children from birth to age 25, while the federal law mandates services from ages 3 to 21 (state law permitting). Second, until Fall 1980 Michigan had a two-stage process for developing each child's Individualized Educational Program (IEP): the first was an Educational Planning and Placement Committee (EPPC), the second was an IEP committee. The federal law mandates one process, and requires placement decisions to be based on the IEP. Michigan, this Fall, created a new decision-making mechanism, which meets the mandate and intent of the federal law.

The findings from our cases thus reflect the impact of Michigan's special education law at full implementation, and P.L. 94-142 at an early stage of

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[1]The age range for children mandated to be served is the only provision that is superceded by state law; thus, only states mandating services to 3-5 and 18-21 year olds must comply with P.L. 94-142 in this area.

implementation. Because the two laws are similar in intent and procedures outlined, it is possible to view our findings as indicating the impact of P.L. 94-142 at relatively full implementation, since the state law has been at work for five years.

Institutional Responses to the Act: Central Findings from our Cases

Procedures and Programs

- Response to the Act has been much greater in educational agencies than in non-educational agencies, as might be expected. Central elements of P.L. 94-142 that have come to shape the educational process--for example, parent involvement in decision-making, service in the least restrictive appropriate environment--have not influenced the medical, social welfare, and mental health service systems. Thus, families experience a discrepancy in treatment from service system to service system.

- The state, the county and local districts of our study children have developed a more formal, consistent, and comprehensive educational evaluation and program planning process. Procedures from district to district are more consistent than historically. Monitoring of program implementation has remained a difficult process.

- P.L. 94-142 has led districts to develop a wider range of placement options for our study children and their handicapped peers. The development of these new options has generally been in the form of adaptation of existing programs, or new ways of using such programs, not creation of new programs.

- A broader base of educational evaluation information is considered in determining eligibility and program design for our study children under P.L. 94-142. Adaptive behavior and functioning carry greater weight than in the past, and a broader range in types of evaluation instruments is considered appropriate.

- The regular and special education service systems in the districts of our study children are very slowly developing mechanisms to work together to share resources, plan, provide mutual support, and so on. Mechanisms get developed when problems become urgent. Developing formal procedures for coordination appear to be the responsibility of special education administrators, many of whom are overloaded with monitoring, compliance and related paperwork.

- The county in which our study children live has not yet developed an adequate continuum of services at the preschool level for handicapped children. Particularly lacking are mainstreamed options supported by the public schools. These options exist among private

service providers, but there has been no support for them by LEAs or the county.

- In general, the educational evaluation and program planning process has been expanded quite significantly in the last few years, but actual classroom programs have changed much less--in kind and structure. The effect of this can be likened to putting a high-powered new engine in an old car body: pressures for comprehensive and individually appropriate services have increased more than the availability of of those services.

Roles and Responsibilities

- Special and regular educators involved with our study children have generally made concerted efforts to accommodate to their new roles vis-a-vis each other, and in relation to parents.

- Regular educators are slowly and painfully gaining the confidence and skills to work with handicapped children and their families, while special educators are going through a lot of self-evaluation concerning their role in educating handicapped children. Special educators are finding it difficult to acknowledge that regular educators can competently meet the needs of handicapped children.

- Most professionals are honestly struggling to accommodate and be responsive to parents' views, although communication frequently remains formal and superficial.

- Some of the behavior we've observed in professionals working with our study children is survival behavior; responding to new demands, pressures, requirements, at the same time continuing to meet traditional demands and pressures, and maintaining patterns of behavior in use for years.

Institutional Responses to the Act: Problematic Aspects

- There continues to be very little coordination between service systems serving handicapped children. While the Act implies that the education system is the lead system, the medical, mental health, and social welfare systems continue in their old patterns of service, frequently undermining the intent of P.L. 94-142.

- While P.L. 94-142, through its mandated procedures, has improved the effectiveness of the special education process as a whole, there remain gaps and irregularities in the process that undermine the effectively working elements. Identification, for example, proved to be an extremely haphazard, traumatic, and sometimes destructive element of the process for some of our study children. In half our study cases, parents had no guidance on what to do next after learning that their child was handicapped. Who the parents contacted, or who happened to recommend something

determined the experiences that followed. Monitoring of program implementation, and then adjusting the program pieces to reduce stresses on the children, was another element missing from most of our study children's programs.

- In a few of our study cases educational institutions responded to the mandates of P.L. 94-142 only when pressed to do so by parents or county compliance officers. They implemented only those elements of the Act that they were pressed to implement.

- The Act itself provides no guidance to administrators, teachers, therapists, parents, and others to figure out how to re-align relationships, roles, responsibilities--nor could it. Nonetheless, the human and individual responses make up the quality of implementation. Thus, differential response make the quality of implementation appear to vary significantly from district to district, and sometimes school to school.

Implementation of the Central Provisions of the Act

While we will present in detail our findings concerning least restrictive appropriate environment and parent involvement, we are including our central findings in the areas of protection in evaluation procedures, procedural due process and development of an individualized educational program.

- Procedural Due Process: The school districts in our study were generally very passive in informing parents of their own and their children's rights under P.L. 94-142 (the Act does not require them to be active). Parents uniformly received prior notice of decision-making meetings, and permission was sought to do evaluations or make program modifications. But most of our parents learned about their rights from other parents or advocacy groups. Due process procedures were only resorted to once in all our cases; nonetheless, their existence modified the decision-making process in the manner of making professionals more responsive to parents' feelings.

- Protection in Evaluation Procedures: The county in which our study children live is rich in diagnostic services and professionals. All our study children have had fair, thorough, and multi-faceted evaluation over the years. This provision of the Act was very useful in that sense. Nonetheless, in most of our cases a different kind of constraint in this area emerged: evaluation findings were frequently not helpful in pointing to a particular program and placement option. The nature of data from evaluations frequently didn't resolve placement questions; other information had to do that. Also, available evaluation instruments don't seem to yield clear, useful information on prognosis or program needs for young children.

A more minor but persistent problem was the continued use of unnecessarily technical language in evaluation reports. In a number of our study cases parents and professionals used evaluation findings to prove or defend a position they already held before the findings were presented (parents used independent evaluations thus).

- Individualized Educational Program: The main implementation issue for many of our study cases in this area was a tendency for specific objectives to be stated rather briefly and superficially. Teachers might do detailed planning, but they generally did it after the IEP was signed. There was a feeling that parents didn't need to be in on, and wouldn't be interested in, all the pedagogical details.

Findings Regarding Least Restrictive Appropriate Environment

We found significant variability within our sample in interpretation and implementation of the least restrictive appropriate environment (LRAE) provision of P.L. 94-142. By variability we don't mean actual placement--this obviously would vary from child to child; rather we mean the assumptions and evidential factors brought to the decision-making process, and the way options were considered. Factors influencing interpretation and implementation of LRAE in our study cases included: availability of resources and services; historical organization, roles, and patterns of service provision; the unique portrait of ability and need presented by each child; the pressure to create a new educational decision-making process with new rules; lack of a commonly held set of goals for educating individual children in our sample; and lack of a clear definition for the term "appropriate". We found that special and regular education teachers, therapists, school administrators and parents are all feeling strong pressure to implement the LRAE provision of the Act; but that nothing in their previous experience has prepared them for this task. Nonetheless, within constraints imposed by extremely limited resources, both professionals and parents are committed to the concept of placement in the least restrictive appropriate environment, and many felt this concept to be the heart of P.L. 94-142.

Our findings in the area of LRAE included some central tendencies and trends, as well as significant variability in interpretation and implementation. Some of the consistent trends, across all our cases, were:

- in placement decision-making situations, consideration of more options, that is, a wider range, than would have been considered even a few years ago;

- a general sense that mainstreaming was the philosophical, if not the actual, goal for placement for our study children;

- at some point, for all our study children, considerable negotiation between parents and professionals concerning what environment is least restrictive yet still appropriate; and

- a tendency on the part of parents of mildly or moderately handicapped children to push for a more mainstreamed program than professionals involved felt was appropriate.

With respect to the specific factors influencing interpretation and implementation of LRAE we found the following:

Availability of resources and services: The county in which our study children lived offered a wide range in types of classroom programs and support service options. In general, this plentiful service availability created a context of flexibility, and a sense that an appropriate classroom option could always be found somewhere for a particular child. Adequacy of resources and options created room for negotiation between parents and professionals, because the situation was rarely so delicate that a child might not receive any services.

Nonetheless, the effect of high county-wide service availability was very different in small and mid-sized districts in the county. In small districts it had little effect on range of local placement options available to handicapped children. In fact, plentiful services in the few largest of the county's ten districts acted as a disincentive for the majority of small districts to develop in their own schools a continuum of classroom placement options. Thus, children and their families had to adjust to what was available by traveling to placements far from home. The problem of small districts providing an adequate continuum of placement options to a small number of children with a variety of handicapping conditions is a difficult one. Its resolution should not fall on the shoulders of children themselves and their families. Yet fragile education budgets in the small districts involved would have been significantly disrupted by even marginal redistribution of resources.

In the larger districts in the county there was frequently significant pressure on study children to use the well-developed special education service system fully, even when parents wanted to use only selective elements of the system, and there was evidence that a child was functioning well in regular classes. In two of our nine cases there was significant pressure on the families to have their child placed in a self-contained special education class, because the specially trained teachers would be best able to provide an appropriate program. In one case it was clear that the child was thriving in a regular classroom setting; in the other, the issue was giving a Down's Syndrome child at least a chance to make it in a regular class setting--not to pre-judge the child's functioning based on a label.

In spite of plentiful special education services, the county in which our study children lived offered no mainstreamed public preschool options. A number of study children would have benefited from such options, although a few others were quite effectively served in available self-contained programs. Because public schools don't provide a regular preschool that could serve as a foundation for a mainstreamed program, the LRAE mandate and intent is difficult to achieve at the preschool level through public schools.

Plentiful regional availability of special education services thus proved in our cases to be a necessary, but not sufficient, condition for achievement of LRAE. Uneven geographic and age-related distribution of services within the county, and inordinate pressure to use services fully in a few cases, constrained achievement of LRAE for some of our study children.

Historical organization, roles and patterns of service provision: Historically separate, uncoordinated special and regular education administrative and service systems; and specialization and fragmentation of roles and programs within the special education service system, both influenced interpretation and implementation of the LRAE mandate to various extents in our study cases. These factors had a particularly strong influence in the cases where children had multiple, complex service needs, or were in shared-time programs involving regular and special education classes.

The LRAE mandate created in our study cases a number of situations requiring coordination. These included: procedures for and actual extent of communication around the program needs of individual children; the working through of IEPs that described mutually reinforcing components of a total program; consultation time and technical assistance for regular classroom teachers; program coordination for children in shared-time programs involving placement in both regular and special education classes; genuine integration of self-contained special education classes into the life of their schools; and the need for special and regular education staff to be actively supportive of each other in new roles.

We found that time pressures and role expectations among both special and regular educators made routine coordination difficult, even when both were situated in the same school. Yet because a number of our study children had three or more major transitions in classroom setting on a daily basis, this routine coordination was urgently needed to ease the adjustment to new classmates, behavior expectations, academic expectations, curricular content, and so on. In the instances in our study when teachers could make connections--with questions, illustrations, activities following a common theme--we observed the children to adjust more quickly.

IEP committee meetings, and IEP reviews, created opportunities for coordination; but these were less routine and had much less effect on the daily environment experienced by children. Also, the tendency in many IEP

meetings was to add pieces of a total program together like patchwork, rather than to build toward a common goal or design. We found a hierarchy of influence limiting give and take in IEP meetings, with special educators having a more dominant role than regular educators.

A central constraint to achievement of LRAE for our study children being educated largely in mainstreamed environments--four of our nine children--was lack of preparation and ongoing support for the regular classroom teachers serving the children. Both psychological (that is, enough knowledge and time to adjust to the idea itself) and technical preparation would have been useful, according to these teachers. Nonetheless, special educators in the relevant districts had neither the time nor the training to work in a technical assistance role with other teachers. The quality of the mainstream experience for our study children was determined largely by the personal qualities--initiative, coping skills and so on--of the classroom teacher struggling him or herself to find a way to meet the handicapped child's needs.

Lack of coordination was found in our study to be a problem within the special education service system, as well as between special and regular education systems. Specialization and fragmentation of roles and program design caused children to be served, in a few cases, in three or four extremely different special education environments. For example, one of our study children participated in EMI and EI programs simultaneously. The environments in these two class settings were different in behavioral and academic expectations. More commonly, children had speech, occupational, or physical therapy, or teacher consultant services that simply were not coordinated with the main EMI, EI, or POHI classroom program. Most special education teachers working with our study children have been trained to focus on one, or at most two, handicapping conditions. While they focused as much as possible on the total child, their specialized training had a strong influence on the ways in which they interacted with study children. Most of the special education teachers and therapists working with our study children made efforts to find time to meet together to coordinate program components--but these efforts were informal and ad hoc.

The extent of a continuum in institutional settings available for placement also affected provision of least restrictive appropriate environment for some of our study children. In terms of institutional settings our study children and their parents were faced, in a number of instances, with rather stark choices, for example between the county POHI center and a regular classroom, or between the county TMI/SMI center and an EMI classroom in a regular school. There was, for example, no POHI classrooms in regular schools in most of the districts in the county, and no TMI/SMI classrooms in regular schools. There was then a stark choice in institutional settings for some of our study children: from largely mainstreamed to physically isolated. In a few of the districts in the county the need for building more options into the continuum of settings available has begun to be addressed in a few of the districts of our study children--for example, a new POHI facility is being built, attached to an elementary school, a class

for severely mentally impaired children has been opened up in one district in an elementary school. Thus, the building of a continuum is slowly being forged. Meanwhile, it depends where a child lives in the county whether he or she will have access to new choices.

Coordination between special and regular education service systems, specialization and fragmentation of roles and programs within the special education service system, and extent of continuum in institutional settings, were all factors that influenced coherence among a particular child's educational environments, and therefore their restrictiveness. We came to discover in our study that coherence of a child's total program is a crucial, albeit problematic, element of LRAE. The problems evident in our study of lack of coordination among program elements, and between environments serving a child, suggest to us a tension between the necessity of certification and classification and the intent of the least restrictive appropriate environment mandate. Certification and classification are exclusionary, and appear to justify maintenance of a separate, specialization-based service system for handicapped children. The intent of LRAE is inclusionary and integrating. Sorting these contradictory pressures out was a continuing concern for many professionals, and parents, in our study.

The program and placement decision-making process: We found in our study that the position, or point of departure, from which decision-making meetings began, the openness of participants to each other's views, and the actual process itself leading to decisions, all influenced the way LRAE was interpreted for a child. Related to these, the general lack of a commonly held set of goals for educating particular children, and lack of an operational definition for the term "appropriate," made the process of arriving at consensus more difficult. When decision-making meetings began with no conclusion already drawn by participants about most appropriate placement, parents and professionals were less likely to feel "railroaded" by the process of choosing an option. Also, advantages and disadvantages of any particular placement option were more likely to be brought out. In a related fashion, when parents' and professionals' perspectives on LRAE for a particular child were given equal weight, and considered seriously, consensus on a particular program and placement was more likely to be achieved, and a reasonable placement decision (or compromise) arrived at. Because there was usually a good deal more consensus among professionals than between parents and professionals in most of our study cases, professionals' consciousness of the sensitive use of their authority was critical to an open decision-making process.

Formal procedures at LRAE decision-making meetings tended to constrain full parent participation in discussions. At most meetings evaluation findings were presented, school progress in various areas reviewed, and options laid out for the coming year, all by professionals, before parents even had a clear role to play at the meeting. Only in the few cases where parents were explicitly encouraged and asked to share their perspective were parents active in the first part of meetings.

Lack of commonly held goals for the education of particular children, and lack of an operational definition for the term "appropriate" in P.L. 94-142 left those participating in LRAE decision-making meetings with few objective criteria to evaluate various placement options. For the majority of children in our study it was not immediately apparent that a mainstreamed or self-contained placement was appropriate--choice depended on the short and long term goals formulated personally by parents and professionals, the quality of alternative environments under consideration, and the way individuals interpreted appropriateness. Because participants frequently brought differing expectations of the purpose of children's education to bear on decision-making, and had a stake in different possible outcomes (e.g., a special education would want his or her service system used), there was in our study wide variability in the way appropriateness was defined, within and across cases.

The child's handicapping condition. Each child in our study presented a distinctive portrait of abilities and disabilities, a unique style of adaption to his or her handicapping condition. A number of aspects of this portrait were found in our study cases to influence interpretation and implementation of LRAE. These included: clarity with respect to cause, diagnosis, and prognosis for a particular child's handicapping condition; presence of multiple handicaps; ease of classification under a particular program label; degree of consensus on a child's main programmatic needs; and a child's adaptive responses to his or her disability.

In two of our cases lack of clarity as to cause, diagnosis and prognosis for a particular child's handicap led to shifting classifications, determination of educational needs, and program designs over the years. Both these children have been thought to be educable mentally impaired and learning disabled, at one point simultaneously. For both, it has been hard to ascertain the causes of their learning problems. In the case of one of these children his IEP committees continue to experiment with new placements after five years of searching for an appropriate environment.

For multiply handicapped children in our study the difficulty in interpreting least restrictive appropriate environment has been in sorting out and prioritizing the behavioral and educational impediments to optimal functioning, and designing a program that provides the optimum treatment for the greatest deficit. It has also meant identifying the disability that might be at the root of other problems.

Determination of a child's main programmatic needs often involved consideration of trade-offs in program focus in our study cases among different aspects of a child's development. This was especially true for multiply handicapped children, but was a factor in decision-making for almost all study children. Although cognitive, socio-emotional and physical development are in actuality closely intertwined, in a number of our study cases choice of one or another placement has been seen to mean enhancement of development

in one area, at the expense of another. Related to this issue, we found that the classification system mandated under P.L. 94-142 tended to lead particular children's IEP committees to choose among alternative environments focusing on different kinds of needs. Although dual or triple classification (for example, as educable mentally impaired and emotionally impaired) was present in a few of our cases, it was generally discouraged in our study districts, even when appropriate.

Each child in the study played a key role in defining his or her own educational needs: by indicating through behavior or verbally how happy and comfortable he or she was feeling in particular settings. Especially for the mildly to moderately impaired children in our study, each child's own unique attitudinal and behavioral response, rather than the objective label solely, suggested appropriate placements.

Parent Involvement

The findings regarding parent involvement in our study cases shed light on three central issues: the implications of genuine versus cosmetic parent involvement; the factors differentiating the way various parents used their rights under the Act; and the implications of school systems taking either a pro-active or reactive stance in informing parents of their rights and responsibilities. Threaded through these issues was the often difficult behavioral and attitudinal adjustment process that parents and professionals had to go through in meeting new responsibilities under P.L. 94-142.

Two kinds of factors have differentiated the way our various study parents have used their rights under P.L. 94-142: institutional/environmental factors, external to the particulars of the situation; and individual factors such as the status, backgrounds, and personalities of the participants, the history of a particular family's relationships with the schools, and the nature of a particular child's needs. Institutional factors drew parents into an activist role in three of our cases when the parents saw significant shortcomings or problems in the institutional systems serving their children. Whether the problem was lack of adequate resources, an institutional philosophy that appeared to be harmful to the child, or a disorganized classroom program, parents who by their nature were not activist became quite assertive to protect their children.

On the other hand, in one case in which the child involved was arguably receiving a very high level of service and attention, his parents played a very active role in monitoring his education and participating in decision-making because they didn't really trust professionals' judgments, and had a fairly difficult history of interaction with professionals. Their activism could be found on every issue and at every level of decision-making with respect to their child's program. In another case, continuing difficulty in ascertaining a particular child's capability and needs over a period of years kept parents involved at a high level in program decision-making.

Two factors that we might have expected to clearly have an influence on parent involvement--social status of the family, and parental knowledge of the provisions and intent of P.L. 94-142--did not prove to be seminal in differentiating involvement among our families. While almost all our study families started out with an extremely limited knowledge of P.L. 94-142, this fact never impeded parents' willingness to assert themselves to get their children's needs met. In fact, parents frequently familiarized themselves with the major provisions of P.L. 94-142 only when they had to take an active role in decision-making. Even then, parental knowledge of their rights was often inexact or vague. Lower income, "blue-collar" parents were generally just as willing to engage the schools in battle when the situation called for such a necessity as higher social status parents. The former were also just as interested in monitoring their child's progress as the latter. Personal or situational factors that most clearly influenced parent involvement included: personality of the parents, history of involvement with the schools, attitudes of key professionals, clarity of diagnosis of a child's handicapping condition, and, as discussed above, parental feelings concerning adequacy of services offered.

In general in our study cases, when there was deeper parent involvement in various aspects of a child's program, regardless of the motive, there was more tension between parents and professionals. The reasons for this increased tension included: a feeling on both sides that the old rules no longer applied, but no one yet knew the new rules well enough to feel comfortable with them; at times a feeling in professionals that their expertise was being slighted or ignored; and for parents, an opportunity for the first time to ventilate powerful feelings about past treatment from professionals, and the profound fact of being a parent of a handicapped child. The working out of a new role for oneself, within the context of making crucial decisions about a child's present and future, inevitably brought emotion to the decision-making situation.

One benefit of deeper, more genuine parent involvement was in many cases a more just placement for a child--more so, quite frequently from the parents' perspective than from the professionals'. For parents another benefit was a sense of renewed control over their own and their child's life. In some cases, parents who became active in decision-making on behalf of their own child came into contact with other parents trying to do the same or who had already done so--they entered the "community" of parents of handicapped children and felt part of a community for the first time in many years.

Most teachers of children in our study recognized both the costs and the benefits of genuine parent involvement, and they both appreciated and resented active parents. All teachers recognized parent involvement as a key provision of P.L. 94-142, and since the most common attitude to implementing the Act was compliance with the minimum of necessary disruption, we never found any overt resistance to parent involvement. But when resentment was present, even covertly, parents picked it up and responded.

The parent involvement provision of P.L. 94-142 mandated a number of administrative mechanisms to ensure parent involvement in their children's programs. These include adequate prior notification of meetings regarding their child's program (planning, decision-making, review), notification before any planned changes in daily or weekly program, access to all records kept on their child, and efforts to time meetings so parents can attend. Even more basic, parents are to be informed of all the above and related rights for them and their children under P.L. 94-142. We have noted a number of trends in development of these mechanisms in our cases. The trends generally relate to school efforts to satisfy the intent as well as the letter of the law.

We have found that the schools generally do not take an active role in informing parents of their and their children's rights, although school staff willingly provide information when asked. This is in compliance with the letter of P.L. 94-142, although perhaps not the intent, since schools are not required to be active here. Most of our study parents picked up information on P.L. 94-142 from other parents of handicapped children, in parent-support groups, or from advocates. None of our parents are fully aware of all the provisions of P.L. 94-142; some have full knowledge of selected provisions, some have a general sense of the requirements and intent of the law. In general, our study parents have acquired information on particular provisions on a "need-to-know" basis: our least active parents probably have least knowledge of their rights under the law. (It is hard to know which is cause and which is effect here, although we have found the "need-to-know" incentive a strong one.) In the area of informing parents about the law, the schools have generally met the letter rather than the spirit of the law.

In very few cases have the prior notification or access to records requirements not been met. In almost all our cases, efforts have been made to arrange meetings so that at least one parent could attend. When necessary, parents have been consulted by phone. The intent as well as the letter of the law was clearly met in this area. With respect to records a more complicated picture emerges. Probably only one family had full copies of everything in a child's school records, although most of our families have some of the documents in their children's files. Schools clearly take a reactive position in this area, probably fearing the time and cost involved in voluntarily providing records to parents. In a few of our cases, parents have not been aware that school systems often have two files on handicapped children--a regular file and a special education file. Thus, they have sought information from what they thought was the only file. Also, not being given a list of what was in the files, some of our parents have not known what to ask for.

Generally, our study parents have been informed of evaluations and received reports of evaluation findings. In only a few instances have evaluations been conducted without the parents' knowledge or consent. Rarely are evaluation findings translated into non-technical language,

and this has frustrated parents in almost all our cases. Parents of mentally impaired children in our study find numerical scores of I.Q., D.Q. (developmental quotient), or abilities particularly frustrating. One parent spoke for a number of others when she noted a tendency for most evaluation reports to focus on what a child can't do, rather than what he can do (the exception being developmental profiles).

Perhaps the clearest single indicator of the impact of the parent involvement provision of P.L. 94-142 on our study families has been the nature of the process of IEP and IEP review meetings. The IEP meeting by its very nature is extremely stressful for parents. As one mother noted "a group of professionals are sitting around a table discussing the future of your child." The professionals' control over that child's future, their authority and status, and their numbers--one parent is usually surrounded by five or six professionals--make it difficult for parents to assert their perspectives.

One of two patterns of interaction was evident at most IEP meetings. In the first the parent is an integral part of the discussion, periodically commenting on the issue of the moment. In the other, the professionals present and discuss material, with the parents remaining largely silent; then, at some point, an advocate or one of the professionals asks: "What do you think, Mrs. and Mr. _____?" The reasons for the presence of one or the other of these two patterns can be found in the structure of the process outlined by the IEP chair, in the professionals' level of awareness of how the parents might be feeling, and in the parents' own sense of their role at the meeting.

The general stages of almost all IEP meetings, except for those involving grievances, problems in program delivery, and related special matters, were: presentation of evaluation and progress reports, laying out of program options for the future, discussion of the options, and choice of one of the options. At some meetings a child's eligibility for special education services under one or another category was discussed, approved, or re-confirmed. This general meeting structure tended in all our cases to leave parents silent for the first half of the meeting; therefore, the first interaction pattern described above predominated at most IEPs. The exception occurred when parents were invited to share their perspective on a child's progress, or when the parents inserted themselves into the presentation.

We found that when parents were asked concrete, specific questions, and shared concrete information integral to decision-making, then they were truly involved in decision-making. Also, when it was apparent that the professionals at the table are actually listening to and considering what the parents were saying, and not just being polite, then the parents were truly involved in decision-making. When the school psychologist at one recent IEP asked the parents not to just note what they wanted but to explain why they thought a child should be in a regular first grade class, the parents made a fundamental

contribution to that meeting. Unfortunately, parents are too fearful and professionals too unsure of how to bring parents into the discussion in most cases. Thus, integral involvement of parents in planning, decision-making and review meetings is one impact of P.L. 94-142 yet to be fully felt.

All of our study parents are significantly more involved in planning for and deciding about the educational program of their handicapped children than they would have been if their rights were not defined in law. Because the changes in relationships mandated and implied in P.L. 94-142 are fundamental, it is easy to understand why both parents and professionals are still struggling to come to terms with those changes in late 1980. The important point emerging from the evidence in our cases is that, except in rare instances, they are struggling. As parents have become more involved, too, this involvement has both enhanced their sense of self as decision-maker, and led to more effective programs for their children.

Conclusions

In examining the impact of P.L. 94-142 on nine handicapped children and their families living in one county in Michigan, we have by no means provided a vehicle for surveying the effects of that law on the general population of handicapped individuals. Rather, we have provided a vehicle for a small number of families and those serving them to share their experiences in coming to understand their rights and responsibilities under the law, and then attempting to translate that understanding into new patterns of behavior and interaction. The strength of our study has been in the depth to which we have had the opportunity to go, thanks to the openness and sense of responsibility of both parents and professionals.

We have come to agree with Edwin Martin, after working with our case families for two years, that P.L. 94-142 is indeed the most important legislation for the handicapped ever passed. We have observed firsthand the human impact of that legislation. Painful adjustments have had to be made. Rights spelled out in the law have still had to be fought for, in some cases. Resources have had to be found by school districts to meet new responsibilities. Teachers have had to find ears to listen to parents, and parents' words to express their ideas and feelings. Handicapped children have found themselves, in at least some cases, more clearly in the mainstream of educational and social life.